

**PREMIER'S ADVISORY COUNCIL
FOR PERSONS WITH DISABILITIES**

**REALIZING THE VISION
OF COMMUNITY LIVING**

**REPORT OF:
THE COMMUNITY SERVICES TASK TEAM**

MAY, 1992

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EXECUTIVE SUMMARY



INTRODUCTION

The Community Services Task Team was established by the Premier's Advisory Council for Persons with Disabilities in the fall of 1990. The Task Team was assigned to look at the appropriateness and adequacy of services in meeting the needs of persons with disabilities living in the community. The specific objectives were:

- To review the policies of GAIN for the Handicapped.
- To examine the policies relating to the provision of medical equipment, technical aids, attendant care, special services and other support systems which promote community living.
- To evaluate alternate methods of providing income assistance and other essential support systems in order to identify how they can be provided in ways which promote economic independence and personal autonomy.
- To provide recommendations to Council regarding policies and programs; coordination of the services offered by various ministries; and other ways of providing community services which are more responsive to the needs of adults with disabilities.

The Task Team adopted a number of approaches to completing its assignment:

It contacted the provincial Ministries of Advanced Education, Training and Technology; Health; and Social Services for information on their programs and had subsequent discussions with the Ministries of Health and Social Services to review information and to discuss the appropriateness of existing programs.

It invited submissions from interested groups and the general public.

It held public hearings in Castlegar, Kelowna, Prince George, Vancouver and Victoria. Fifty-two presentations were made at the hearings and 103 written submissions were received.

It commissioned three research studies:

- **Catalogue of Programs and Services for Persons with Disabilities and a Discussion of Possible Program and Service Development Projects**
- **A Critical Review of the GAIN Program**
- **The Disability Income System in Canada: A Literature Review and Policy Analysis**

On the basis of the information provided by the above studies, by investigations conducted by the G. Allan Roeher Institute of issues facing persons with disabilities and by the submissions it received, the Task Team prepared a discussion paper and circulated this paper in November, 1991. The responses to the discussion paper and its draft recommendations were not only positive, but contained useful suggestions, and many have been incorporated in this final report.

The overall conclusion of the Task Team is that a policy vacuum exists with respect to services for persons with disabilities in B.C. No provincial ministry in B.C., or indeed in any other province in Canada, has developed a comprehensive statement of policy to guide the development of programs and services for persons with disabilities. "Policy" is defined in this report as a statement of intent or purpose expressed in the form of legislation or formal document. The consequence of the failure to establish a policy is that programs are developed in isolation from one another, lack coherence and are frequently inadequate.

Given this policy vacuum, the first and foremost recommendation of the Task Team is that the provincial government, in conjunction with the Premier's Advisory Council, develop and establish in legislation an overall policy to guide the development of programs and services for persons with disabilities. The policy must be anchored in a social development perspective and must ensure that services:

1. are individualized;
2. are universally available regardless of type of disability or ability to pay;
3. are respectful of consumer choice and determination;
4. facilitate and support the full and equal participation of people with disabilities in community life, including education, employment, recreation, culture and family life;

5. have a clear rationale and are organized in a manner that is accessible to consumers and ensures effective service delivery;
6. recognize the equality rights of people with disabilities, including the right to self determination, the right to privacy, and all other rights enjoyed by other citizens.

The second major conclusion of this report is that the majority of persons with disabilities are poor; do not have appropriate housing; encounter difficulties in finding suitable transportation; and lack adequate medical services, technical aids, equipment, supplies, support services and Long Term Care. Hence, in every aspect of life, programs for persons with disabilities are frequently inadequate and inappropriate.

Given this lengthy list of program deficiencies, the second major recommendation of the Task Team is that a guaranteed adequate income be established for persons with disabilities. In order to ensure adequacy, the benefits provided by this program must equal the low-income cut-off lines set by Statistics Canada. Further, the Task Team recommends that a guaranteed adequate income for persons with disabilities be viewed as a stepping stone towards a guaranteed income for all Canadians. This income plan must be accompanied by a national assurance plan which would cover the costs of equipment, supplies, support services and other costs incurred because of the condition of disability.

The third major conclusion is that the current definition of disability and the process of determining eligibility for benefits are unsatisfactory and must be reformed. Hence the third major recommendation is that the provincial government adopt the World Health Organization definition of disability, that the eligibility process be based on the self-declaration approach, and that the determination of the condition of disability be made by a panel composed primarily of persons with disabilities.

The recommendations of the Task Team are listed on the following pages and are also contained in the chapters to which they pertain.

RECOMMENDATIONS

RECOMMENDATION NO. 1

THAT the Provincial Government adopt the definition of disability used by the World Health Organization. This definition would be used for all provincial programs.

RECOMMENDATION NO. 2

THAT the Provincial Government create a joint government/community "committee" to develop an eligibility process based on the self-declaration approach, utilizing a panel composed largely of persons with disabilities to make the final determination of eligibility. This determination must focus on the condition of disability and be divorced from conditions such as employment.

RECOMMENDATION NO. 3

THAT Income Assistance rates be increased to the low-income cut-off lines established by Statistics Canada and used by the National Council on Welfare.

RECOMMENDATION NO. 4

THAT legislation be enacted that ensures that the Minister of Social Services adjust Income Assistance rates to reflect changes in the Consumer Price Index.

RECOMMENDATION NO. 5

THAT the federal government withdraw the ceiling set for Canada Assistance Plan contributions and that a joint federal/provincial task force be established to review the CAP fiscal arrangements.

■ **RECOMMENDATION NO. 6**

THAT time limits on participation in education and vocational upgrading be removed in the GAIN legislation and that persons with disabilities have full access to employment and volunteer opportunities.

■ **RECOMMENDATION NO. 7**

THAT GAIN Legislation allow for larger work-related expense exemptions and that the "tax back" rate not exceed 50 percent of total income from employment.

■ **RECOMMENDATION NO. 8**

THAT the distinction between "unearned" and "earned" income be removed.

■ **RECOMMENDATION NO. 9**

THAT individuals who live in group homes should directly receive their full income assistance benefits. Their shelter and food expenses must not exceed two-thirds of this amount.

■ **RECOMMENDATION NO. 10**

THAT all persons with disabilities be declared "likely to be in need" so that income or needs testing is not required to receive these services.

THAT asset and income restrictions be relaxed so that any person with a disability may access necessary benefits and services he/she may require.

■ **RECOMMENDATION NO. 11**

THAT both the provincial and federal governments establish a definition of disability based on the World Health Organization definition which clearly separates the condition of disability from employment considerations.

▣ **RECOMMENDATION NO. 12**

THAT an efficient eligibility process be established which respects the dignity of the individual and acknowledges the unique and particular needs of each individual.

▣ **RECOMMENDATION NO. 13**

THAT the province develop an individualized approach to a person's needs in the areas of goods and services.

▣ **RECOMMENDATION NO. 14**

THAT serious consideration be given to the rewriting of the GAIN Act in language that can be understood by those who interpret as well as those who receive the information.

▣ **RECOMMENDATION NO. 15**

THAT the provincial government, in conjunction with federal and municipal governments, take steps to increase the supply of affordable, accessible housing.

▣ **RECOMMENDATION NO. 16**

THAT all housing programs provided by government be reviewed and streamlined and that one ministry have the responsibility for housing and housing-related services.

▣ **RECOMMENDATION NO. 17**

THAT shelter allowances be raised to allow actual shelter expenses to be reimbursed up to an established ceiling based on average cost of rental accommodation in the community where the person resides.

▣ **RECOMMENDATION NO. 18**

THAT residential services, supports, shelter allowances and adequate respite be provided to parents with dependent adults living at home.

▣ **RECOMMENDATION NO. 19**

THAT a coordinated, multimodal transportation system providing equal transportation service to persons with disabilities be developed, with accessible conventional buses, parallel vehicles, taxis, and accessible ferries.

THAT BC Transit provide increased and more flexible funding for handyDART service.

THAT BC Transit increase handyDART vehicle fleets, extend hours of service, make greater use of taxi back-ups throughout the province and develop uniform standards of service.

THAT all ride requests for handyDART be met, as is the case with the conventional transit system.

THAT the hours and days of service provided by handyDART in a community be the same as the hours and days of service of the conventional transit system in the same community.

▣ **RECOMMENDATION NO. 20**

THAT the priority system for rides on handyDART be eliminated.

▣ **RECOMMENDATION NO. 21**

THAT the province-wide planning program for a fully accessible transportation system, as announced by BC Transit, address the issues of regional disparity, varying standards of service and appropriate service in rural areas.

▣ **RECOMMENDATION NO. 22**

THAT all bus passes and discount rates available to users of the conventional transit system be made available to handyDART users throughout the province.

▣ **RECOMMENDATION NO. 23**

THAT the annual bus pass, now available to GAIN recipients, be made available to all low-income persons with disabilities wherever transit services are available to the general public throughout the province.

▣ **RECOMMENDATION NO. 24**

THAT GAIN transportation allowances be increased to accurately reflect the transportation costs to the individual.

▣ **RECOMMENDATION NO. 25**

THAT the use of BC Transit's Scrip System Taxi Saver Program be expanded to include smaller and more rural communities throughout the province.

▣ **RECOMMENDATION NO. 26**

THAT an additional discount rate for the Taxi Scrip Program be made available to all low-income persons with disabilities.

▣ **RECOMMENDATION NO. 27**

THAT the provincial government provide financial support to taxi owners for the conversion of vehicles to meet the accepted standards for accessible taxis.

▣ **RECOMMENDATION NO. 28**

THAT assistance be provided for the purchase, maintenance and insurance requirements of personal, private, accessible vehicles for persons with disabilities who are excluded from existing transportation services because of where they live or other circumstances such as low income.

■ **RECOMMENDATION NO. 29**

THAT policy governing the provision of technical aids, equipment and supplies for people with disabilities reflect the principles of universal accessibility for all members of society, regardless of ability to pay, place of residence and/or type of disability.

■ **RECOMMENDATION NO. 30**

THAT criteria for eligible equipment be expanded in consultation with consumers to ensure that all necessary equipment and supplies are available for independent living.

■ **RECOMMENDATION NO. 31**

THAT medical coverage reflect the full range of needs of persons with disabilities, including alternate therapies, non-prescription medical drugs and supplies, as insurable expenses under the B.C. Medical Services Plan and Pharmacare Program.

■ **RECOMMENDATION NO. 32**

THAT access to information on services and procedures be improved for all persons with disabilities by making them available in alternate formats and in plain language.

■ **RECOMMENDATION NO. 33**

THAT sign-language interpreters for the deaf and hard of hearing, and intervenors for the deaf blind be provided in medical situations at no charge to the user.

■ **RECOMMENDATION NO. 34**

THAT policies in the Ministry of Social Services give increased choice of distributors for purchase of equipment and supplies.

▣ **RECOMMENDATION NO. 35**

THAT assessment for eligibility for medical services, technical aids, equipment and supplies be based on effective results for the person rather than cost.

▣ **RECOMMENDATION NO. 36**

THAT a mechanism be implemented to ensure that policies address equipment maintenance at provincial and/or national standards.

▣ **RECOMMENDATION NO. 37**

THAT the service delivery system be reviewed and reorganized so that there are no gaps in equipment delivery and so that persons with disabilities get simple and quick access to equipment; this would include an efficient process for pre-authorization, pre-payment and reimbursement.

▣ **RECOMMENDATION NO. 38**

THAT the provisions for acquiring emergency supplies and repairs be streamlined through an efficient pre-approval system.

▣ **RECOMMENDATION NO. 39**

THAT a provincially-coordinated equipment loan program be implemented.

▣ **RECOMMENDATION NO. 40**

THAT dental benefits under the Ministry of Social Services be increased and dental coverage be expanded to include all required dental services.

THAT dental coverage be expanded to include all persons with disabilities.

▣ **RECOMMENDATION NO. 41**

THAT user fees for therapeutic services be eliminated for low-income persons with disabilities.

▣ **RECOMMENDATION NO. 42**

THAT support services to enable persons with disabilities to participate in the community be provided on a free and universal basis to persons with disabilities.

▣ **RECOMMENDATION NO. 43**

THAT the provincial government initiate provincial/federal discussions to change or develop federal cost-sharing programs which ensure the universal provision of appropriate support systems to persons with disabilities in Canada.

THAT the provincial government declare persons with disabilities "likely to be in need", so that support services can be delivered on a universal basis in accordance with the recent federal/provincial agreements regarding CAP funded programs.

▣ **RECOMMENDATION NO. 44**

THAT a complete review and reorganization of the entire system of support services be immediately undertaken in consultation with the community of disabled persons, and that the mandate to provide the full range of support services which enable persons with disabilities to participate in the community be clearly enshrined in the provincial legislation governing these programs. These support services must include assistance for participation in work, school, family life, and community activities, and must meet the principles delineated above.

■ **RECOMMENDATION NO. 45**

THAT the name of any program(s) providing support services to persons with disabilities reflect the concepts of "support" or "assistance", not "care". The name must also reflect a commitment to provide service to support all the activities of community living, not just service in the home.

THAT many types of assistance that attendants are presently not allowed to perform be demedicalized and performed by attendants when the consumer directs the performance of these tasks.

■ **RECOMMENDATION NO. 46**

THAT the assessment procedure to determine eligibility and amount and type of service in the Long Term Care Program be substantially revised, in consultation with persons with disabilities, to ensure that assessments reflect the needs of person with disabilities, are consistent, and do not violate privacy rights. Specifically:

THAT the current 120 hour maximum in the Long Term Care system be eliminated.

THAT the current preset levels of care in the Long Term Care Homemaker Program be eliminated and replaced with an assessment procedure based on criteria relevant to a client's actual need for service. Service guidelines must be flexible and include all services necessary for persons to live productively in the community, including employment, education, family and community activities.

THAT availability of family members not be considered part of an assessment.

THAT the current Long Term Care assessment procedure be replaced with an application procedure which places the responsibility for description of service needs and documentation with the client. This application procedure must be developed in consultation with the community of persons with disabilities.

THAT the assessment/application procedures be redesigned to ensure that they do not violate the privacy rights of persons with disabilities. Only information relevant to service delivery must be collected and maintained on file: notations not relevant to a person's need for service, such as attitude, attire, smoking or drinking habits, must not form any part of an assessment/application procedure.

THAT the criteria used to determine the amount of support services for persons in the community must not be the same as the criteria used for institutional assistance.

■ **RECOMMENDATION NO. 47**

THAT support services be available for persons with temporary impairments and as a means to prevent permanent disability. Buffer hours must be included in all assessments to accommodate emergencies or temporary changes in need.

■ **RECOMMENDATION NO. 48**

THAT until a universal system is developed, the daily fee for service in the Long Term Care Homemaker Program be immediately eliminated or replaced with a weekly or monthly fee that does not discriminate on the basis of degree of disability.

THAT larger standard deductions for daily living expenses, employment and disability be allowed, as well as a new deduction for medical expenses. Individuals with expenses above the standard amounts must be allowed to itemize deductions.

THAT family or spousal income not be considered part of assessable income for Long Term Care or Ministry of Social Services homemaker assessments. If this income is included, exemptions must be significantly increased so that persons marrying persons with disabilities will not be relegated to the poverty level.

■ **RECOMMENDATION NO. 49**

THAT support service delivery options include a full range of models, including individualized funding, brokerage models, an Improved Enhanced Consumer Participation Model, and service through homemaker agencies. Clients should have the choice of which service delivery system best suits their needs, as well as choice of agency and worker.

THAT the restriction that family members cannot be hired as attendants/homemakers be removed.

■ **RECOMMENDATION NO. 50**

THAT an ongoing consumer committee be established to ensure that this goal, and others, are effectively met.

■ **RECOMMENDATION NO. 51**

THAT regulations be enacted for all programs providing support services, in consultation with the community of disabled persons, to protect the rights of participants and ensure that service standards are established and met.

THAT an independent appeal mechanism be established to review decisions on all aspects of service including eligibility, amount, and type of service for all support service delivery systems.

THAT consumers be guaranteed the right to access their files.

■ **RECOMMENDATION NO. 52**

THAT wages to homemakers/attendants be substantially increased to reflect the variety of skills required and the value of the work. Training and implementation of service standards should be done in consultation with clients, so that training is relevant and effective. Service delivery systems must be accountable to the persons receiving the service.

■ **RECOMMENDATION NO. 53**

THAT priority for service delivery be given to agencies that best meet the criteria of federal/provincial cost-sharing programs and to agencies which provide higher wages to workers.

■ **RECOMMENDATION NO. 54**

THAT the provincial government, in conjunction with the Premier's Advisory Council, develop and establish in legislation an overall statement of policy to guide the reform and development of programs affecting people with disabilities. This statement must ensure that services:

- 1) are individualized;
- 2) are universally available regardless of type of disability or ability to pay;
- 3) are respectful of consumer choice and determination;
- 4) facilitate and support the full and equal participation of people with disabilities in community life, including education, employment, recreation, culture and family life;
- 5) have a clear rationale and are organized in a manner that is accessible to consumers and ensures effective service delivery;
- 6) recognize the equality rights of people with disabilities, including the right to self-determination, the right to privacy, and all other rights enjoyed by other citizens.

■ **RECOMMENDATION NO. 55**

THAT the Cabinet Committee on Social Policy be given responsibility for establishing a review process to ensure that all legislation, policies and programs are consistent with the policy statement by December, 1994.

■ **RECOMMENDATION NO. 56**

THAT the Provincial Government implement a policy on information for people with disabilities which is based on the following principles:

- Information is clearly stated in plain language.
- Information is provided in a format accessible to the individual.
- Information must be complete and indicate all available options.
- Government personnel are obliged to provide consumers with full information, including information on program policies.
- Persons with disabilities have access to their own files.

■ **RECOMMENDATION NO. 57**

THAT the provincial government develop a single point of access for information on the comprehensive array of services available to people with disabilities.

■ **RECOMMENDATION NO. 58**

THAT the provincial government implement a universal dispute resolution process which would apply to all programs for people with disabilities.

ACKNOWLEDGEMENTS

From its inception in 1988, the Premier's Advisory Council has been urged to review the adequacy of community services for persons with disabilities. This report represents the Council's response to the many requests for a review, and marks the first step in achieving a vision for community living for persons with disabilities. Throughout the review, persons with disabilities identified both problems and solutions in a very clear and frequently gripping fashion. In large measure, the report has been shaped by the insights of persons with disabilities and the Council and the Task Team owe a debt of gratitude to the many individuals who wrote briefs and attended the public hearings.

The Task Team also wishes to thank the support staff of the Premier's Advisory Council, Eunice Munro and Phoebe Yong, for their help and unfailing courtesy in preparing this report.



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PREFACE

This report was first issued as a discussion paper in November of 1991 and circulated to all individuals who, either on their own behalf or as representatives of organizations, had made submissions to the Task Team. The covering letter asked if the discussion paper contained any inaccuracies or omissions and requested support for the recommendations contained in the paper. Responses were received from 33 organizations, 14 individuals and five ministries of the provincial government.

The responses were overwhelmingly positive. A list of organizations endorsing the discussion paper appears in Appendix D. Some indication of the tenor of the feedback can be gained from the following comments:

- *The draft paper is a major step forward in clearly analyzing and articulating a comprehensive approach to disability.*
- *We particularly like the analysis and the suggested changes to the underlying philosophy of assistance to persons with disabilities.*
- *An enlightened and impressive paper.*
- *Well researched, comprehensive and forward-thinking document.*

Joan Smallwood, the Minister of Social Services, noted that:

The material you have compiled represents a significant effort from many service consumers, citizens and interested community experts.... From this first review I can confirm that there are no serious errors or omissions, and I thank you again for your useful commentary of British Columbia's programs for the disabled.

Several responses were extremely helpful in pointing to ways of improving the discussion paper. Among the many useful suggestions were the following: shortening the report, eliminating inconsistencies and ranking the recommendations in order of priority. The Task Team considered all suggestions and incorporated many into this report.

Only one response was received which disagreed with the thrust of the discussion paper. In addition, the B.C. Aboriginal Network on Disability Society expressed concern with the absence of information in the paper regarding Aboriginal people in British Columbia.

Several respondents suggested that the Task Team prepare cost estimates of its recommendations on the rationale that the report would be incomplete without such estimates. After much deliberation, the Task Team decided to disregard this well intentioned suggestion for two reasons. First, the Task Team is of the view that it is entirely appropriate for a research group to present a comprehensive review of needs without giving attention to the resources required to meet those needs. In the last analysis, the decision to develop programs to meet needs can be taken only in the context of complete information including the resources available and the competing demands for these resources. Such information is only available to governments and ministries at the point that budgets are assembled.

The second reason is much more pragmatic. The Task Team simply did not have the time or the expertise to develop cost estimates. It is appropriate to note here that the Task Team did not have the resources of a Royal Commission. Task Team members worked on this project on a part-time, voluntary basis. A staff member of the Premier's Advisory Council was seconded to provide assistance, but again on a part-time basis.

From the very first meetings the Task Team was concerned about the implementation of recommendations. The Task Team took the position that gathering information and writing a report represented the first, and arguably the easiest, part of the process of reform. The Task Team initially planned to use the interim period when the discussion paper was being reviewed to begin work on implementation. However, the very process of review interfered with this laudable objective: it was clearly premature and indeed presumptuous to begin work on implementation prior to receiving support and feedback.

Nevertheless, some progress has been achieved. The overall thrust of this report — that the first priority is for the provincial government to establish an overall policy for persons with disabilities, that this policy should be anchored in a social development approach to social policy, and that implementation of this policy should begin by substantial reforms to the Guaranteed Available Income For Need Act — has been communicated to government and to the disability community, and has received support. In addition, the Premier's Advisory Council gave complete approval to the discussion paper and is in the process of developing plans to implement the recommendations. These plans include:

- ▶ presenting the recommendations to the Cabinet Committee on Social Policy and working with relevant Ministries towards implementation of the recommendations;
- ▶ working in concert with community groups which have been established to improve policies and programs on income support; housing; transportation; technical aids, equipment and supplies; support services and Long Term Care;

- ▶ taking the initiative to develop new community groups in order to advocate for changes.

Because of its commitment to changing policies and programs for persons with disabilities, the Task Team will meet on an annual basis to review progress and identify barriers to progress.

Before turning to the body of the report, a few words of introduction are necessary. The mandate of the Task Team did not include education and employment, since these are the subjects of other projects of the Premier's Advisory Council. The mandate also specifically excluded children, and hence this report is concerned with community supports for adults. Finally, it should be emphasized that the following report is concerned with issues common to all disabilities. The Task Team did not concentrate attention on any one disability, but attempted to identify needs which cut across and affect all disabilities.

CHAPTER ONE

The Premier's Advisory Council for Persons with Disabilities was established in 1988 with a mandate to "review, advise on and make recommendations with respect to government programs and policies with a view to improving the quality of life of persons with disabilities in B.C." The full statement of objectives of the Council is contained in Appendix A.

The Council decided that the most effective way to review policies and programs was to form Task Teams. These teams would be charged with the responsibility of investigating a set of policies and reporting back to the Council with recommendations for change. The first team appointed was given the assignment of studying "issues related to the enforcement of Section 3.7 of the B.C. Building Code — the section on building requirements for persons with disabilities." The Task Team concluded its investigation and submitted a report in November, 1990. Implementation of the Task Team's recommendations is now underway.

The Community Services Task Team, the second team to be struck by the Council, was established in the fall of 1990. The mandate assigned to the team was to examine the services required to enable adults with disabilities to live in the community. This report describes the Task Team's work, the methods by which it collected information, the conclusions and the recommendations presented to the Premier's Advisory Council.

The specific objectives designed by the Task Team and approved by the Premier's Advisory Council are as follows:

1. To review the policies of GAIN for the Handicapped.
2. To examine the policies relating to the provision of medical equipment, technical aids, attendant care, special service and other support systems which promoted community living.

3. To evaluate alternative methods of providing income assistance and other essential support systems in order to identify how they can be provided in ways which promote economic independence and personal autonomy.
4. To provide recommendations to Council regarding policies and programs, the coordination of the services offered by various ministries, and other ways of providing community services which are more responsive to the needs of adults with disabilities.

The membership of the Task Team and their professional and work affiliations are listed at the beginning of this report.

The Task Team began its work by reviewing and refining its mandate, and by adopting a statement of philosophy to guide its actions. The Task Team then contacted the provincial ministries of Advanced Education, Training and Technology; Health; and Social Services, and requested information from these ministries on all programs for persons with disabilities. The Task Team subsequently held meetings with the first two mentioned ministries to review the information collected and to solicit opinions from ministry personnel regarding the adequacy and appropriateness of existing policies and programs.

The Task Team invited submissions from associations and groups in the disability field, from individuals with disabilities, from parents and from the general public. The Task Team developed an outline to guide the submissions (see Appendix B) and held five public hearings in CASTLEGAR, KELOWNA, PRINCE GEORGE, VANCOUVER and VICTORIA. Fifty-two submissions were presented at the hearings and 103 written submissions were received.

In addition, the Task Team commissioned three research studies: Catalogue of Programs and Services for Persons with Disabilities and a Discussion of Possible Program and Service Development Projects; A review of the Gain for Handicapped Program; and a Review and Policy Analysis of the Disability Income System in Canada. (Summaries of these studies can be found in Appendix F and copies of the full reports are available from the offices of the Premier's Advisory Council). Members of the Task Team also acquainted themselves with the findings of significant research studies that have been carried out in Canada in recent times. Among the most useful reports were those conducted by the G. Allan Roeher Institute in Toronto, **Poor Places**, and **Income Insecurity**, and the study completed by the Parliamentary sub-committee chaired by Dr. Bruce Halladay. A complete listing of the reports reviewed during the course of the Task Team's work is contained in Appendix C.

A STATEMENT OF PHILOSOPHY

At the outset, the Task Team identified the need for an explicit statement of philosophy to guide its work and to provide a benchmark for reviewing programs. The Task Team decided to adopt the statement on equality developed by the Premier's Advisory Council and based on the Canadian Charter of Rights and Freedoms. The statement has guided the work of the Task Team in reviewing existing policies and programs and in formulating recommendations for change. In view of its significance for the Task Team, the statement is reproduced below.

The pursuit of equality in a substantive way means that two important aspects must be addressed. First, there must be respect for individual dignity and autonomy and second, provision must be made for equal opportunity to participate in society.

Respect for individual dignity means that persons with disabilities must be recognized as citizens with abilities with equal status to that of other citizens. Supports and benefits provided to persons with disabilities should therefore be viewed as a means to enhance their abilities and provide for full integration into society.

Respect for personal autonomy means that individuals have the right to exercise choice in all aspects of their lives. Autonomy also means that individuals must be in a position to make informed choices and have the right to take risks.

In order to foster equality of opportunity in the community, adequate personal and financial supports must be available to those who need them. Assisting persons with disabilities to achieve their full potential means that personal supports must meet their individual needs.

In keeping with the concept of respect for individual dignity and autonomy, the Council recognizes the need for input from persons with disabilities in shaping policy recommendations to governments.

Further, the Task Team believes that access to information is a fundamental right to effective participation in society by persons with disabilities and that information within the control of government should be generally available. Therefore, the Task Team adopts the principles enunciated by the Ombudsman in the report, **Access to Information and Privacy**, released in 1990. These principles are contained in the following excerpts from the Ombudsman's report:

...individuals must be empowered to participate meaningfully in the processes of government which affect themselves and their communities. Fundamental to such ... participation is effective access to public information held by government.

The right of public access to government information is a basic incident of democratic participation in government, and does not require justification on the basis of any particular need. Information should not be kept unnecessarily confidential. Such a practice helps to create an atmosphere of mistrust and can lead to misinterpretation where information is partially disclosed.

It is the recommendation of this office that the basic policy should be that information within the control of government is generally available to the public. Exceptions to this general rule should be specific, few in number and generally subject to discretionary disclosure if there is no reasonable expectation that harm would result.

APPROACHES TO SOCIAL POLICY

Given its commitment to a philosophy of equality, the Task Team reviewed approaches to social policy in order to identify an approach which would support this philosophy. The three principal approaches to social policy are residual, institutional, and social development. These approaches and the reasons for selecting the social development approach are briefly outlined below.

The residual approach is grounded in the philosophy of rugged individualism. This perspective holds that individuals are essentially self-reliant and independent, can purchase the social and other services they require, and can rely on an extensive network of family, work-related and neighbourhood resources for support. The residual approach has gained favour with many governments not only because of the values it proclaims, but because of its apparent, but frequently not realized, potential for reducing the costs of social programs. Social policies based on residualism provide benefits and services to citizens only as a last resort, in times of crisis, and on the basis of demonstrable and evident need.

By contrast, the universal or institutional approach to social policy is based on the recognition that all citizens require some form of public assistance at some point in their lives. The assistance may take the form of health care, day care, public education (including subsidies for university education), old age security or residence in a care facility as a senior citizen.

Given the universality of need, programs should be provided as a right and an entitlement. Programs based on the universal approach are comprehensive in coverage yet simple to administer, since they eschew complex regulations in the determination of initial and continuing eligibility. They are provided in a way that treats applicants and recipients in a dignified and respectful manner. Perhaps the best examples of universal programs which were at one time available only in a highly residual fashion and to the rich, are education and health care.

The social development approach to social policy builds on and extends the principle of universality. In addition, social development calls for an integration of social and economic policies, so that the social and economic policies are given equal priority. The social development approach is also unequivocal in advocating that those affected by social and economic policies should have an opportunity to contribute to their development and implementation. It needs to be noted that the social development approach has yet to be implemented in most Western societies. With the possible exception of some Scandinavian countries, social development represents a sought after rather than a realized approach to social policy.

During the course of the review of different approaches to social policy, the Task Team recognized that policies and programs for adults with disabilities have been created by adding onto existing programs, rather than creating new and distinct ones. In fact, the philosophy of mainstreaming, which has been a most significant influence in the development of services for people with disabilities, has argued against the establishment of unique programs. However, one limitation of the philosophy of mainstreaming is that additions to inadequate and inappropriate programs designed for the non-disabled population will, when extended to persons with disabilities, also be inadequate and inappropriate.

The argument is convincingly established by pointing to the quintessential residual program — social assistance. In all provinces social assistance programs were established to provide financial aid on a short term basis and only when other sources of income were exhausted. In addition, the amount of financial aid is so inadequate that all recipients live below the poverty line.

Extending social assistance programs to provide income for persons with disabilities has two very unfortunate consequences. First, it ensures that "Canadians who are disabled will be poor" (The G. Allan Roeher Institute, 1988, p.1). Second, the requirement of demonstrated financial need is applied to equipment, attendant and home care services. Programs and services are then provided as a consequence of financial need rather than in response to the condition of disability. This stands in distinct contrast to the universal approach to health care where illness, not financial resources, is the determining factor.

In the view of the Task Team, GAIN was never intended to meet the needs of persons with disabilities and it is, therefore, not surprising that it is a most unsatisfactory program both in terms of providing adequate financial assistance and in meeting the unique service needs of persons with disabilities. The argument with respect to financial assistance is developed further in Chapter Two but it is useful here to note the limitations imposed on provincial governments by the Canada Assistance Plan (CAP). The CAP is the major funding vehicle of the federal government to assist provinces in providing financial assistance and social services. The CAP has two funding components "welfare" and "assistance". The former refers to social services which are provided regardless of financial circumstances, and the latter to financial assistance where eligibility is determined by financial need. However, as noted above, the distinction is largely academic for persons with disabilities since funding for both their service and financial needs has traditionally been provided under the assistance provisions of CAP.

However, the Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities of 1989 brought about a change in the assistance provisions of CAP. Individuals requiring services that are disability specific, such as attendant care, can be considered as "likely to be in need". If implemented by the provinces, neither income testing nor user fees would be required. It is important to add that the change represents an opportunity for provinces, rather than a requirement, and at the time of writing only a few provinces had seen fit to take advantage of this opportunity.

If provinces do adopt this change, services for persons with disabilities will move from a residual to a more universal approach. Nevertheless, the process of determining who is "likely to be in need" will pose problems, and the contentious issue of the definition of disability and of the process of determining eligibility, are addressed in a later section of the chapter.

Even if the above change is incorporated into practice other CAP problems remain. For example, the Welfare funding side to CAP prohibits funding of education, recreation and cultural services, and of individualized service plans which are all essential components of comprehensive community services for persons with disabilities. To complicate matters further, the assistance provisions of CAP permit funding of individualized service plans but only through a means test. It is apparent that like GAIN, CAP was never intended to meet the needs of persons with disabilities, and is riddled with inconsistencies.

Given its commitment to the philosophy of equality, the Task Team decided that the social development approach provides the most potential for charting a course for policies for persons with disabilities. Adopting the social development approach could change the philosophy of mainstreaming to "upstreaming" — to leading the way in social policy. Thus, the disability community and policy makers committed to a social development approach would attempt to develop policies for persons with disabilities which would be at the cutting edge of social policy rather than seeking integration with mainstream and frequently unsatisfactory programs. The case for the social development approach is assembled in the following section.

THE CASE FOR THE SOCIAL DEVELOPMENT APPROACH

There are four principal reasons for the social development approach to social policy. First, the combination of residual and universal policies which have characterized Canadian social policy have not worked. They have resulted in an unequal distribution of income whereby the top fifth of the population receives approximately 40 percent and the bottom fifth approximately 5 percent of the national income, and in high levels of unemployment and of poverty. (See among other sources, Ross, 1987, and McQuaig, 1987). Of particular importance for this review is the fact that these policies have failed to provide sufficient opportunities for paid employment and adequate incomes for persons with a disability.

The second reason is that disability is not an abnormal and exceptional condition and hence is inappropriately dealt with by policies rooted in residualism. In one of the community hearings, a representative of the Brain Injury Association described non-disabled persons as "temporarily able-bodied who, through sickness, accident, or the ageing process, will become disabled." The change in status from able-bodied to disabled is not a question of if but when!

The needs of persons with disabilities should ... not be thought of as special, any more than the needs of those without disability might have been seen as special had those with disabilities designed the world initially. If the needs of one group are seen as special, then they become pitted against the needs and rights of the rest of the population. ... But if the assumption is that these needs and rights are not in fact special, then the discussion is about the best and most expedient way of changing systems so that they take disability, a rather unexceptional human condition, into account (The G. Allan Roeher Institute, 1990).

Third, a distinct advantage of the social development approach is that it pushes policy-makers to give priority to prevention. If disability is a normal and usual phenomenon, rather than an isolated condition affecting only a few, then measures to prevent disability are necessary. The argument is presented in a forceful fashion by an eminent U.S. sociologist, Irving Zola, who has himself become disabled. Zola develops his argument by using some very basic examples. Thus building homes without grab bars and non-slip tiles in bathrooms contributes to accidents in homes. More dramatic examples concern the failure to give adequate attention to automobile safety to establish low speed limits, and to prohibit the sale of guns and other weapons. Zola claims that the failure to "recognize that the entire population is at risk and that seeing people with a disability as different, with special needs, wants and rights" has prevented us from recognizing the appropriateness of a universal approach to social policy (Zola, 1990).

The social development approach recognizes that environments are a significant force in shaping the lives of persons with disabilities.

Disability rises from the failure of the social environment to adjust to the needs of people with disabilities rather than the incapacities of persons with disabilities to adjust to the requirements of society. This new definition of disability recognizes that improvements in the status of persons with disabilities requires alterations in the external environment rather than changes in individual functional and economic skills (Jongbloed and Crichton, 1991, p.33).

Fourth, the social development approach is supported by human rights legislation. The Equality Rights Section of the Charter of Rights and Freedoms has been interpreted to mean that public sector programs must be designed and delivered to ensure "equality of results". This provision is intended to eliminate the problem of systemic discrimination which has, in the past, resulted in unequal access to programs and services for persons with disabilities. A commonplace example of systemic discrimination is a building with stairs and no elevators. While discrimination may not have been intended by the architect and builder, the consequence is to deny access to people with disabilities.

While interpretation of human rights legislation may well continue for some time, a clear sense of direction can be discerned from the interpretations which have been made thus far. Public funding of programs and services will, in all probability, require that these services enable persons with disabilities to live in an independent fashion in the community. Further, services cannot infringe on the rights of persons with disabilities to enjoy privacy and freedom of choice guaranteed by the Charter of Rights and Freedoms. As will become evident in this report, many programs for persons with disabilities violate these provisions.

THE DEFINITIONAL ISSUE

The provision of benefits and services to persons with disabilities has been plagued by two difficult and contentious issues: the definition of disability and the eligibility process. An appreciation of these difficulties can be obtained from the following discussion which concludes with the Task Team's suggestions for reform.

The difficulty of developing a definition of disability is revealed by the fact that governments across the country have not been able to agree on a common definition. Indeed, as a draft report of the Disability Determination Project in Ontario reveals, there are a number of different definitions currently in use in Canada (Ministry of Community and Social Services, 1991). The definitions vary on a number of dimensions: inclusiveness, relationship to employment, and the methods used to determine the condition of disability.

Inclusiveness

The variation with respect to the criteria of inclusiveness is illustrated by pointing to the contrasting examples of B.C. and Quebec. B.C. excludes consideration of social and economic factors in determining eligibility for benefits under the Guaranteed Available Income for Need Act, while Quebec requires that these environmental factors be taken into account.

Relationship to Employment

Perhaps the most crucial and contentious aspect of determining eligibility for benefits is the relationship between the condition of disability and employment. An Ontario medical adjudicator notes that "there is an inherent difficulty in transposing 'diagnoses such as impaired, handicapped and disabled' to a condition such as 'permanently unemployable' which is not medical and harder to define" (Aldis, quoted in *Transitions: Report of the Social Assistance Review Committee*, 1988, p.149). For all intents and purposes, the federal and provincial governments have redefined the condition of disability to one of employability!

Nevertheless, some differences do exist. For example, complete unemployability is required in order to qualify for benefits under the Canada Pension Plan, whereas, another branch of the federal government, Revenue Canada, defines disability as a restriction in the activities of daily living.

Length of the Condition of Disability

Again, legislation across the country differs with respect to length of time of the disability. B.C. requires that the condition be permanent, whereas others soften the requirement somewhat. Thus the Ontario definition refers to a "prolonged state", Quebec to an "indefinite condition" of 12 months or longer, and Alberta as "persistent".

The consequence of this aspect of the definition is that persons with significant, but temporary and reoccurring disabilities, are excluded from benefits. However, the Income Tax Act refers to a "prolonged" disability, and the interpretation of "prolonged" by Revenue Canada is that the condition has lasted twelve months or more.

Severity

Across the country a uniform approach to the criteria to determine the severity of disability is not evident. Although each province requires that an applicant be limited in his/her ability to work, other criteria have been set that must be met before disability benefits are granted. British Columbia's legislation is a good example of criteria which go beyond the applicants employability. In order to qualify for "handicapped" status under the GAIN program, it has to be established that the applicant's disability is "sufficiently severe that:

- a) the individual requires extensive assistance or supervision to manage normal daily functioning, or;
- b) as a direct result of the disability, the individual requires unusual and continuous monthly expenditures for transportation, or for special diets, or for other unusual but essential and continuous needs."

This definition excludes many persons whose chronic conditions limit their ability to work, but who lack clearly identified requirements of extensive assistance or continuous monthly expenses.

THE ELIGIBILITY PROCESS

Persons with disabilities who require either financial assistance or services under the GAIN Program must satisfy two sets of requirements: they must comply with regulations of the GAIN Act concerning financial need, and they must be judged to be permanently disabled and unemployable by a physician. The final determination of eligibility is made in the Health Services Division of the Ministry of Social Services.

In the Task Team's opinion, the current eligibility process in B.C. is unsatisfactory. It is unsatisfactory with regard to financial provisions because, as noted above, the GAIN Act is a very residual legislation and was not developed with the interests of persons with disabilities in mind. In essence, the residual approach is based on a highly suspicious view of human nature: by and large, applicants are not to be trusted and hence must be subjected to rigorous tests to ensure that they comply with regulations. When applied to persons with disabilities, who in many instances lack confidence because of their disability, this approach serves to further discourage and alienate.

The current approach to eligibility in B.C. is also unsatisfactory because of its reliance on the clinical judgements of physicians. While some may agree with the opinion of the medical adjudicator noted above that the conditions of "impaired", "handicapped" and "disabled" are medical and definable, it is questionable whether physicians' judgements on these conditions are consistent. On the contrary, the evidence is that "clinical judgements even when directed solely at the question of impairment are far from uniform and objective". (Transitions: Report of the Social Assistance Review Committee, 1988, p.148). In her comprehensive review of the eligibility process in the U.S., Stone cites numerous studies which found significant variations in clinical judgements.

She concludes, "it is unlikely that the accuracy and consistency of disability determination decisions can be improved very much, given the limits of the diagnostic technology on which they are based" (Stone, 1984).

REFORMING THE DEFINITION AND THE ELIGIBILITY PROCESS

The social development approach demands that the current definitions and processes of determining eligibility be reformed. The social development approach takes a generous rather than skeptical view of human nature, and hence a definition and a process which builds self-confidence and esteem is required. The Task Team concurs with the view of the Social Assistance Review Committee in Ontario that the World Health Organization's definition of disability should be adopted in both federal and provincial legislation concerning persons with disabilities.

A handicapped person is one who is handicapped as the result of an impairment and a disability for a prolonged period of time. Impairment means any loss or abnormality of psychological, physiological, or anatomical structure or function. Disability means any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. Handicap means a disadvantage for a given individual that limits or prevents the fulfilment of a role that is normal depending on age, sex, and social and cultural factors for that individual.

The World Health Organization definition focuses attention on the condition of disability, and not on the financial needs and the employability of persons with disabilities. In our view it is crucial to separate these issues in order to focus policies and programs on disability and not on the contextual factors of finance and employment.

As noted in the Preface, the long-term vision of the Task Team is that a guaranteed, adequate income be established for all Canadians and that this vision be tested by introducing the plan for persons with disabilities. The vision also includes a national assurance plan which would provide funds for the services and equipment required because of the condition of disability. Both plans could be evaluated by reforming the existing eligibility process, and this reform should be implemented immediately. The three essential components of a revised eligibility process are: self declaration by the applicant, a review of the condition of disability by an appropriate professional, and a decision by a regional panel. These components are described below.

Self-declaration requires that individuals begin the application process by completing the application form and, if they prefer, in their own homes. In effect the applicant builds and documents the case for eligibility for disability benefits and services. The Ministry of Social Services could assist in a number of ways, such as simplifying the application form, or by supplying examples of completed applications. Persons requiring assistance in completing the forms could gain help from staff members of the Ministry or from advocates of voluntary agencies.

The second component would be an examination by an appropriate professional. However, the Task Team suggests that the range of appropriate professional skills is not adequately captured by the medical profession. The Task Team recommends extending professional examiners to include, at a minimum, psychologists and psychiatrists. Thus a person with a cognitive disability would be examined by a psychologist and an individual suffering from mental illness by a psychiatrist. All professionals would be restricted to providing clinical opinions regarding the physical or mental health of the applicant.

Finally, the reformed process suggested here requires the formation of a panel to make the final decision on eligibility. The panel would be comprised of a majority of persons with disabilities, but would include some professionals. If deemed disabled, the applicant would be eligible for financial assistance, equipment, and/or services.

Despite the innovative nature of this proposal, a significant precedent for the self declaration approach is afforded by the Income Tax Act. All Canadians file an individual tax return, and while these are subjected to a review by Revenue Canada, the responsibility for the initial completion and the provision of information rests with individuals. Given this degree of trust in the capacity and essential honesty of all Canadians, there is no prima facie reason why the same approach could not be applied to persons with disabilities.

A second reason for suggesting that persons with disabilities be involved in determination is that professionals do not have the time nor the expertise to make consistent, reliable judgements, particularly when they are expected to connect conditions of disability with the capacity to work. The literature on self-help groups is convincing in its claim that where professional knowledge and skills are incomplete, the mutual aid approach should be used (see among other sources, Farquharson, 1990). Thus panels mainly composed of persons with disabilities might be much more helpful to applicants in developing plans for education, employment and other activities of daily living than are professionals.

Finally, the self-declaration and panel approach suggested here starts with the individual and gives him/her the responsibility for starting the application process, including planning for the future. Such an approach is empowering and fits the individualized service approach initiated by the Community Living Society in B.C. and the Canadian Association for Community Living (The G. Allan Roeher Institute, 1991).

THE INCIDENCE OF DISABILITY

The most extensive stock of information about the condition of disability is provided by the Health and Activity Limitations Survey conducted by Statistics Canada as a follow-up to the 1986 Census.

The survey counted the number of Canadians with disabilities, itemized the nature of their disabilities and assessed the impact of these disabilities on their daily lives. One of the main purposes of HALS was to measure the labour market activities of persons with disabilities.

Results from HALS indicated that there were 1,768,000 non-institutionalized disabled persons aged 15 — 64 in Canada in 1986. Seven out of every ten persons with disabilities (a total of 1,255,000) reported that they were limited in their capacity to work because of their disability (Statistics Canada, 1990).

Some of the more significant findings of HALS concerned the severity of the disability, educational attainment, and the differential impact of disability on men and women.

Disabled women were much more likely to be inactive in the labour market than disabled men: 71 percent compared with 52 percent.

The severity of the disability had some bearing on the rate of non-participation; persons with a severe disability were much more likely to be non-participants than were persons with mild or moderate disabilities.

Educational attainment was a very important factor for determining labour force status; disabled persons with only a primary level education were almost twice as likely to be non-participants as those who held a post-secondary certificate, diploma or a university degree (Statistics Canada, 1990 p. 2 — 3).

It is important to emphasize that the HALS survey was concerned with the impact of disability on participation in the labour force. Thus attention was focused on the age 15—64 population. However, disability increases with age and over one third of persons with disabilities are aged 65 and older. Given the ageing of the Canadian population, the reinforcing conditions of age and disability will present enormous challenges for the care of the elderly disabled.

In addition to the HALS survey, there are several studies which examine the impact of disability on employment, income and housing (The Standing Committee on the Status of Disabled Persons, 1990 and the G. Allan Roeher Institute, 1988 and 1990). However, this information is derived from studies which take a wide-angled lens approach to data collection and represent environmental scans of the condition of disability. Missing are studies which adopt the zoom lens approach and report detailed information about the difficulties faced by persons with disabilities in finding appropriate accommodation and employment. Hence a final suggestion emanating from this introductory chapter is the need to design and implement action research studies which illuminate the condition of disability as experienced by persons with disabilities in their day-to-day lives. The suggestion is presented as a recommendation in the concluding chapter.

THE FORMAT OF THE REPORT

A word of introduction about the format of the report is required at this juncture. The analysis of the submissions received by the Task Team revealed six major areas of concern: income support; housing; transportation; medical services, technical aids, equipment and supplies; support services and Long Term Care; and harmonization of services. The report devotes a separate chapter to each of these areas of concern and a common format is used to organize the information. Each chapter begins with an introduction to the issue, contains a review of existing policies and programs, identifies needs and gaps in services noted in the submissions and in the literature, and finally presents recommendations for change.

RECOMMENDATIONS OF THE TASK TEAM

■ RECOMMENDATION NO. 1

THAT the Provincial Government adopt the definition of disability used by the World Health Organization. This definition would be used for all provincial programs.

■ RECOMMENDATION NO. 2

THAT the Provincial Government create a joint government/community "committee" to develop an eligibility process based on the self-declaration approach, and utilizing a panel composed largely of persons with disabilities to make the final determination of eligibility. This determination must focus on the condition of disability and be divorced from conditions such as employability.



CHAPTER TWO

INCOME SUPPORT

- I. INTRODUCTION**
- II. POLICIES AND PROGRAMS IN
CANADA AND BRITISH COLUMBIA**
- III. NEEDS AND GAPS**
- IV. SUMMARY**
- V. RECOMMENDATIONS OF THE TASK TEAM**

I. INTRODUCTION

Almost one-half (45 percent) of the persons and organizations making submissions to the Community Services Task Team commented on the crucial importance of the Guaranteed Available Income for Need (GAIN) Program for persons with disabilities. This emphasis in the submissions prompted the Task Team to commission studies for further analysis on the GAIN Program in British Columbia and the disability income system in Canada.

The following discussion on income support begins with a description of policies and programs now in place, continues with an analysis of their adequacy and appropriateness and concludes with recommendations for change. The analysis is based on information obtained by the Task Team from the submissions and hearings and from the commissioned studies.

II. POLICIES AND PROGRAMS IN CANADA AND BRITISH COLUMBIA

CANADA

The study commissioned by the Task Team and referred to in Chapter One, reviewed the literature on income security for persons with disabilities in Canada and in a selected number of other countries. It concluded that income security for persons with disabilities has been developed as a sub-section of the overall social security system in Canada and lacks an overall coherent philosophy. The income security system for persons with disabilities is in fact not a system at all, but rather a jumble of programs.

The study estimated that:

There are over 175 programs directly connected with disability income. Most of these programs are at the provincial level, and on average, any given province has about 15 major disability-related programs. At the present time, disability income policy comprises an array of programs including income security, tax policy, health and social services, employment-related policies, human rights, social regulations, workplace policies, tort liability, family-based and mutual aid (Prince, 1991).

This study identified three main types of income security plans: universal, earnings-related, and income-tested plans. Universal plans provide income support, usually a flat-rate benefit, to all adults with disabilities and usually to children with disabilities. The benefit is provided regardless of income and work history. Universal plans are usually financed by general government tax revenues.

Earnings-related plans are a form of social insurance. The amount of benefit varies with the amount of income earned before the disability.

Income-tested plans provide disability benefits in which the amount varies according to the amount of other income currently being received by the beneficiary. These plans usually cover adults as well as children. Typically funded by general government revenues, these plans provide basic income support only to people with disabilities who have insufficient income for their needs.

What is distinctive about Canada's approach to disability income protection at the national level is the absence of either a universal or an income-tested program. The Canadian government's main role in providing income assistance to people with disabilities is through the federal-provincial cost-shared Canada Assistance Plan for social welfare. In contrast, most other countries with an earnings disability plan combine it with a universal benefit plan (Prince, 1991).

Ten main shortcomings or flaws of the disability income system in Canada are identified in the Prince study. These are:

- the lack of a vision and an adequate information base on which to guide the system
- the inadequacy of benefits, services and rights
- the marginalization and stigmatization of clients
- the presence of barriers in the system to independence and employment opportunities
- the problem of "creaming" — giving preference in services to persons less rather than more disabled
- the incredible complexity of the system
- the problems of gaps and overlaps between and among programs
- the inconsistencies in programs and other inequities in treatment of persons with disabilities
- the system's inefficiency and wastefulness
- the insufficient emphasis given to prevention of circumstances leading to disability.

Disability income programs for persons with disabilities are based on a philosophy of residualism which holds that benefits and services should be minimal and provided only as a last resort when the resources of individuals and families have been exhausted.

The findings from this study confirm those contained in **Income Insecurity** (The G. Allan Roeher Institute, 1988).

The study highlights are presented below:

- ▶ All provinces provide inadequate benefits. To be disabled in Canada is to be poor and to receive a level of assistance below any of the established poverty lines. Rates are not regularly indexed according to the cost of living. Another serious problem reported was that the shelter component of the income programs is seriously below market rental prices. Many people pay more than the maximum amounts allowed for shelter and use the food allowance portion of their budget to do so.

New Brunswick, Ontario, Alberta and British Columbia have special programs of income support for persons with disabilities. The other provinces allow persons with disabilities to qualify for long-term higher rates and special allowances.

- ▶ Most jurisdictions determine eligibility on the basis of a needs test, rather than an income test. None consider the condition of disability as the sole requirement for benefits.
- ▶ Most provinces require that an applicant have a physical or mental disability that severely impedes her/his ability to be employed. Medical certification is generally required for this purpose. Persons qualifying as "unemployable" receive higher income support and have access to a broader range of benefits.
- ▶ The amount of savings or other assets an applicant is allowed varies widely across Canada. This means that people in some provinces have greater financial security than in other provinces. Most provinces make it very difficult for families to financially assist their family member with a disability, without putting the income entitlement in jeopardy.

BRITISH COLUMBIA

In British Columbia, a patchwork system of private and public insurance schemes results in varied treatment of persons with disabilities. When a disability is a result of an activity where third-party liability can be established, the person with a disability can seek compensation for the resulting loss in future income, the additional required financial resources to purchase disability-related goods and services, and, in some cases, compensation for non-financial losses. The settlement is limited only by the liability insurance and the capacity of the third party to compensate. When liability cannot be established, general insurance coverage for interrupted earnings may provide financial resources to persons with disabilities. These insurance schemes are not universal and are generally only available to some employed, union and professional individuals.

Government-managed and funded income "insurance" programs, such as Unemployment Insurance, Worker's Compensation, Veterans' or Canada Pension Plans and Crime and Victim Compensation may also provide income support to persons with disabilities. This support, however, may be time-limited or insufficient for the individual's or family's needs.

For persons who fall through the "cracks" in the insurance net, the Guaranteed Available Income for Need (GAIN) program provides income based on a calculated level of "need" for the individual or family. The program for persons with recognized permanent disabilities is a sub-category under GAIN, referred to as GAIN for Handicapped. Persons with disabilities may be classified into one of the other programs, other than "handicapped," depending on the nature, severity, and permanence of the disability, and their employment opportunities. GAIN also provides income to seniors, and to individuals and families in financial need.

The GAIN programs are administered by British Columbia's Ministry of Social Services. Under the Canada Assistance Plan (CAP), the federal government cost shares GAIN benefits up to 50 percent based on federal guidelines. Benefits within the federal guidelines to persons "in need" are fully shareable under CAP. Since many persons with disabilities rely on GAIN for their support, the program is outlined here in some detail.

ELIGIBILITY

The GAIN for Handicapped Program is distinguished from other GAIN programs in terms of specific eligibility criteria and benefits. Important criteria for the designation of handicapped status are that the condition is permanent and that all available remedial therapy to reduce the disability has been attempted. In addition, the potential for employment through training and retraining must have been exhausted. The handicapped designation is restricted to persons aged 18 years and older. Finally, the designation of handicapped status is at the discretion of the "Director" who is appointed under Section 23 of the GAIN Act.

Once the handicapped designation is granted, it is permanent even if the designated person's disability at some future date no longer excludes her/him from employment, and even if the disability can be alleviated through new medical treatment or technologies. Persons with disabilities who do not meet the criteria receive a lower level of support even when their circumstances and needs are comparable to a person designated handicapped.

The differences in treatment of persons with comparable disabling conditions, and the additional long-term security of the handicapped designation, provide incentives for persons with disabilities to attempt to be designated handicapped. The handicapped designation also provides for permanent access to non-monetary benefits, such as medical insurance and other health-related goods and services, which are important to everyone.

Applicants for GAIN benefits are required to declare their assets for determination of eligibility. When assets exceed the established limits, the person is expected to liquidate the excess assets.

The GAIN Regulations contain a list of assets which are exempt from eligibility consideration. In general, liquid assets and fixed assets, excluding those deemed necessary for personal use or for employment or business, are considered in the asset test.

The GAIN allowable asset levels vary by category of applicant. The Canada Assistance Plan also has established allowable asset guidelines for cost sharing: these guidelines are higher than the established GAIN levels in B.C.

BENEFITS PROVIDED BY GAIN

The GAIN entitlement (maximum benefit payment) for an individual or family is calculated from a schedule of prescribed allowances. These allowances are general with respect to basic needs and specific with respect to needs beyond the "normal requirements".

The support allowance is the basic amount for eligible recipients based on program category and family size. For each designated "handicapped" person in a family, the support allowance is \$164 more than the corresponding unemployable rate.

GAIN recipients are eligible for a shelter allowance up to a maximum amount. For each designated handicapped person in the family there is a minimum \$75 shelter allowance. If the actual shelter cost is less than the minimum, the actual cost is ignored and the minimum is paid.

In addition to the support and shelter allowances, a number of supplementary allowances are available to GAIN recipients when the need is demonstrated. These allowances are also available to individuals or families that include a designated handicapped individual.

As noted earlier, the benefits provided by all provincial programs, including GAIN, are inadequate. The extent of the inadequacy is discussed in Section III, "Needs and Gaps."

GAIN PAYMENT AND CLIENT INCOME

Once eligibility and entitlement are established, the GAIN payment is dependent upon how much the entitlement exceeds unexempted income received by a person. Income is categorized as unearned or earned income. GAIN recipients are expected to apply for all alternative sources of financial support to minimize their need for GAIN benefits.

Unearned income is not exempt. Entitlements are reduced by the amount of the unearned income, a practice which represents a 100 percent tax.

Generally, unearned income is defined as income from non-employment related sources, such as Unemployment Insurance Benefits, gifts and prize money. Education and training allowances are often treated as unearned income and taxed at a 100 percent tax rate.

Earned income is treated differently. GAIN recipients are encouraged to earn income, and up to \$100 per month is exempt and does not reduce the basic GAIN entitlement. Each dollar of earned income above \$100 is eligible for the enhanced earnings exemption where the entitlement is reduced by \$.75 per dollar of earned income. Those classified employable are also eligible for the enhanced earning exemption of a 75 percent tax on earned income above the flat exemption. Those classified as unemployable may qualify for the enhanced earnings exemption if they are reclassified as employable.

III. NEEDS AND GAPS

The following discussion and analysis of the GAIN program is based on the submissions presented to the Task Team and on the information gained from the hearings held in five communities. It is important to emphasize again that the information obtained by the Task Team confirms the findings from the literature and from studies which have been conducted in Canada, that this province has failed to develop an appropriate philosophical base for its policies and programs for persons with disabilities. It is not surprising then that the Task Team discovered that the GAIN program is inadequate in terms of the benefits and services provided, inappropriate in its administration and, in general, ill-suited to the needs of persons with disabilities.

INPUT FROM SUBMISSIONS ON PROGRAM PHILOSOPHY AND ADMINISTRATION

Comments on the administration of the GAIN Program were given in 72 percent of the submissions on GAIN. Some comments from the submissions follow:

- ▶ Policies are interpreted differently by the Ministry of Social Services' regional offices so that access to information and benefits is inconsistent.
- ▶ When there are administrative delays in receiving benefits, benefits are not granted retroactively.
- ▶ Service discrepancies exist:
 - from one part of the province to another
 - from services for children to services for adults
 - between provincial and federal income support programs.
- ▶ Persons with a non-visible disability are often not informed about GAIN for Handicapped.

- ▶ Application to the program is made difficult because forms must be completed in the office, often without assistance; because some persons with disabilities are unable to understand or access the application process; and because people are not encouraged to have an advocate present during the process.
- ▶ People are frequently not informed of the appeal process.
- ▶ The lack of clear and simple information restricts people's choices.
- ▶ Many materials related to program application are not available in alternate formats required by persons with certain disabilities.
- ▶ A lack of appropriate training among government staff, poor pay and high staff turnover serve to aggravate the frustrations related to administration.

INPUT FROM SUBMISSIONS ON ELIGIBILITY

Many submissions received by the Task Team described serious concerns with the criteria for determining eligibility to the GAIN Program. The input received on the definition of "handicapped" and the asset restrictions is outlined below.

Definition

- ▶ The definition of "handicapped" requires the determination of 'apparently permanent'. Some persons with disabilities do not fit this criteria, such as persons with mental illness, persons with head injuries, persons with temporary disabilities or persons in transition needing short-term or temporary assistance.
- ▶ The requirement that the applicant must demonstrate that she/he has "tried and completed all possible remedial treatment to overcome the disability" is extremely restrictive.
- ▶ The present system requires doctors to determine unemployability. Potential employability is very difficult to assess and is not entirely a medical determination.
- ▶ 'Permanently unemployable' is seen as an inappropriate label in the light of new thinking and advancements in the employment field for persons with disabilities. The criteria for eligibility impose limits on a person's education and employment potential.

The categorical approach of the GAIN program in response to individuals with disabilities is to exclude persons with "temporary" disabilities or persons with declining abilities. For persons with significant disabilities deemed not to be "permanent", their exclusion from comparable treatment to the "permanently" disabled is inconsistent and unfair. Similarly, persons with declining abilities are confronted with increasing needs without a clear indication that they will be eligible for disability-related benefits in the future.

A number of inconsistencies in the GAIN Program confuse and frustrate applicants and recipients. For example, the requirement that applicants for handicapped status have tried or completed all possible training or retraining for employment is in sharp contrast to the policy that applies to persons who have been granted handicapped designation. At this point a person is allowed and indeed encouraged to participate in employment-related "Programs for Independence", programs to assist people in reaching financial independence. Also, persons who have been designated handicapped are entitled to the highest level of earning exemptions under the GAIN Program.

Consequently, it is not surprising that recipients of GAIN for Handicapped benefits view the system as arbitrary, unresponsive and unfair.

Asset Restrictions

A person's eligibility for benefits and programs is affected by allowable asset requirements. These allowable assets may vary according to the category of the income assistance recipient. For example, the allowable assets for a single, unemployable person are \$500, but for a single person on Handicapped Benefits can be as high as \$2,500. This structure of allowable assets makes the application process inequitable, and prevents persons with disabilities from receiving a full range of benefits without substantially reducing personal assets.

Concerns with the declaration of assets for determining eligibility, and with the allowable levels, were documented in the submissions, as indicated by the following comments:

- ▶ Allowable asset levels are too low to account for emergencies and major purchases.
- ▶ The regulations on assets make it very difficult for persons to receive direct financial support from their families.
- ▶ Asset exemptions differ according to the residential situation of a person.

INPUT FROM SUBMISSIONS ON BENEFITS

Seventy-six percent of the submissions reported that the level of financial assistance provided by GAIN for Handicapped Program is entirely inadequate in meeting the income support, shelter, and transportation needs of person with disabilities.

While poverty lines established by various groups and associations across the country differ slightly, the Social Planning and Research Council of B.C. publishes a set of poverty lines on an annual basis and compares them to the benefits paid by GAIN. In 1990, the monthly shortfall varied from 39 percent to 75 percent for five hypothetical families.

The following additional shortcomings of the benefits provided by GAIN were noted in the submissions:

- ▶ There are very few provisions in the GAIN Program that address the extra financial needs that a person with a disability may have. The regulation that authorizes crisis grants has become a catch-all provision but it was not designed to meet ongoing needs such as furniture and clothing. There are mechanisms to provide for essential health items and benefits to give persons starting work a few financial incentives and to grant a transportation allowance to some persons who are designated handicapped. These provisions have been limited rather than expanded. An example is the \$500 dental allowance provided as a GAIN program benefit which has remained unchanged since 1988. Persons receiving GAIN benefits have seen a 30 percent reduction in the services that were previously (prior to 1988) provided by the B.C. Dental Plan.
- ▶ Regular increases in GAIN rates do not occur.
- ▶ The program coverage does not reflect the real costs to people with disabilities, such as medical equipment, supplies, and dental expenses.
- ▶ The "comforts" allowance does not provide people in group homes with adequate disposable income for participation in community and recreational activities.

INPUT FROM SUBMISSIONS ON INCOME

The submissions received by the Task Team reported the following comments on both earned and unearned income provisions in the GAIN Program:

Earned Income:

- ▶ The Earnings Exemption Program has several inconsistencies for those on unemployment insurance, receiving child support or with unearned income.
- ▶ Most submissions indicated that the earnings exemption levels result in disincentives to work.
- ▶ Earnings exemptions are inadequate in that they do not allow for the extra cost of disability.
- ▶ Earnings exemptions make no provision for an ongoing allowance for volunteer activity.
- ▶ GAIN regulations' earnings exemptions place self-employed persons in a "hardship" situation, rather than encouraging the self-employment of persons with disabilities.

Unearned Income:

- ▶ Unearned income is fully deducted from a person's income.
- ▶ Gifts from family or friends are fully deducted and are identified as frustrating any attempts to assist the person with a disability.
- ▶ The program provisions discourage marriage in that family income becomes a determining factor in eligibility after marriage, the implied assumption being that one income can support the needs of two people.

IV. SUMMARY

Chapter One outlined the philosophical position taken by the Task Team and the Premier's Advisory Council that disability is a condition which affects all Canadians. Thus policies for persons with disabilities must be universal and available to all as a right. It is clear from the analysis that GAIN is not based on this philosophy. It is a residual program designed to serve individuals in temporary financial need and was never intended to serve persons with disabilities. There is substantial agreement among persons with disabilities, and in the literature reviewed for this study, that the condition of disability must be divorced from the conditions of financial need and employment. Hence the first conclusion of this section of the report is that residual programs designed to serve individuals requiring income assistance on a temporary basis are inappropriate for persons with disabilities.

The second conclusion is that the benefits provided by GAIN are completely inadequate. This report confirms the findings of all investigations of the needs of persons with disabilities for an adequate income.

The third conclusion is that GAIN is administered in an inappropriate fashion. Income support for persons with disabilities must be provided in a way that recognizes the dignity and self-worth of applicants and recipients. It must be provided in a simple, fair and efficient fashion.

In addition, the need for a community-based, straight-forward, non-intimidating accessible and independent appeal mechanism is emphasized. The GAIN appeal process, while not perfect, is based on these principles. An independent advocacy service would assist persons who want to appeal or obtain a second opinion.

The evidence that persons with disabilities are poor is clear and compelling. There are two reasons for the condition of poverty. First, many persons with disabilities are currently unemployed; and second, their condition of disability requires additional expenses for purchase of equipment, medical supplies, and a variety of support services. Hence, persons with disabilities confront twin disadvantages: unemployment and the costs of support required for community living.

The Task Team has noted that interest in a guaranteed annual income (GAI) as a strategy to end poverty is re-emerging. A recent study conducted under the auspices of the Economic Council of Canada (1991) states that:

The Royal Commission on the Economic Union and Development Prospects for Canada (The Macdonald Commission) advocated a major revamping of our social security system. It proposed that Canada implement a Universal Income Security Program that, in essence, amounted to a guaranteed annual income. The outrageous idea in the 1960's that government should provide a guaranteed income to everyone now became a centrepiece recommendation of a royal commission (Economic Council of Canada, 1991).

The study concludes that:

Labour supply response is an important issue in income maintenance and other social policy evaluation since work disincentives are a powerful argument against such program initiatives. Time and again, suggestions to reform either income support or social insurance programs in Canada have pressed against the fear that altering benefits for those capable of work might prove counterproductive. At its core, the worry is that cash transfers would diminish work incentives. Our results suggest that these fears are largely misplaced (Economic Council of Canada, 1991).

The Task Team is of the view that a guaranteed adequate income should be provided to all Canadian citizens. Such provision is consistent with the Charter of Rights, and it is virtually required in a society which compels 10 percent of the citizens to exist without employment. Canada has in fact achieved a guaranteed annual income with respect to the elderly as a consequence of combining a universal payment, the Old Age Security (OAS), a contributory pension plan (CPP) and an income tested program (OAS/GIS). However, while the structure for an annual income is in place, the benefits provided to some elderly persons, and particularly single women, are entirely inadequate. Guaranteeing an annual income is of dubious benefit if the income is inadequate! We recommend that a second step in the direction of a GAI be undertaken on behalf of persons with disabilities. This step would mean that two groups with a distinct claim on a GAI would be covered, but it is important to add that this claim is advocated here in the context of an overall reform of income security for all Canadians, and not only as a benefit for people with disabilities.

However, persons with disabilities do require a unique program because of the condition of disability. The Task Team recommends that this program should also be available on a national basis, but that the amount would vary according to the needs of the individual. The program would cover the costs of support services, equipment, medical supplies and other costs incurred because of the condition of disability.

V. RECOMMENDATIONS OF THE TASK TEAM

Towards the Social Development Approach

A social development approach to policy for persons with disabilities would begin with the establishment of a national program providing an adequate income. The program would be available to all people with disabilities as a right, but would be counted as income for income tax purposes.

The development of such a program is the main recommendation with regard to income support for persons with disabilities. We recognize that this recommendation may not be implemented in the near future; in the meantime, the following recommendations concerning adequacy, eligibility and administration can be addressed.

- Income Assistance must meet basic needs. These needs are measured by "poverty lines". The National Council of Welfare estimated that the 1990 poverty line for a single adult living in a community over 500,000 is \$14,078. The Social Planning and Research Council (SPARC) determined that the "monthly subsistence costs" of a single male in December, 1989 were \$817.55.

RECOMMENDATION NO. 3

THAT Income Assistance rates be increased to the low-income cut-off lines established by Statistics Canada and used by the National Council on Welfare.

- Once the rates have been set at the poverty line, it is important that cost of living increases be put in place so that income is not eroded by inflation. Recent rate increases have not kept up with the cost of living.

RECOMMENDATION NO. 4

THAT legislation be enacted that ensures that the Minister of Social Services adjust Income Assistance rates to reflect the changes in the Consumer Price Index.

- In February, 1990, the federal government announced a 5 percent ceiling on increases in its share of Canada Assistance Plan financing in B.C. This limit, which was unsuccessfully challenged by the province, will have a negative impact upon income assistance recipients and on the provision of other support services, as the province will have to carry a disproportionate share of the necessary funding increases to income support programs.

RECOMMENDATION NO. 5

THAT the federal government withdraw the ceiling set for Canada Assistance Plan contributions and that a joint federal/provincial task force be established to review the CAP fiscal arrangements.

- Removing Disincentives

The current income support system creates obstacles for persons with disabilities attempting to live independently. For persons seeking to contribute to the best of their ability, programs must acknowledge and foster the individual's vocational capabilities.

RECOMMENDATION NO. 6

THAT time limits on participation in education and vocational upgrading be removed in the GAIN legislation, and that persons with disabilities have full access to employment and volunteer opportunities.

- Under the present system, the government "grabs back" as much as 75 percent of a person's income from employment. Persons who are attempting to earn income through self-employment are also disadvantaged by the current limitation in the earnings exemption scheme.

RECOMMENDATION NO. 7

THAT GAIN Legislation allow for larger work-related expense exemptions and that the "tax back" rate not exceed 50 percent of total income from employment.

- Persons who cannot work often feel unfairly discriminated against because all "unearned income" is deducted dollar for dollar off their income assistance cheque.

RECOMMENDATION NO. 8

THAT the distinction between "unearned" and "earned" income be removed.

- Issue of Empowerment and Access

Arbitrary categories exist in GAIN legislation and policy which limit the individual's choice and ability to live with dignity. One such special category is the "comforts allowance". Most persons living in group homes do not have the opportunity to receive their income directly or have any say on how most of the money is spent; the amount allowed for disposable income — the comforts allowance — is inadequate.

RECOMMENDATION NO. 9

THAT individuals who live in group homes should directly receive their full income assistance benefits. Their shelter and food expenses must not exceed two-thirds of this amount.

- Many persons with disabilities who are not on income assistance lack access to programs and services because of assets and income criteria which exclude them. These include transportation, medical benefits, and support services. A recent agreement between the federal and provincial governments (the Federal/Provincial Review of Fiscal Arrangements Affecting Persons with Disabilities) enables provinces to declare persons with disabilities as "likely to be in need"; since this group of individuals is likely to be in need, no income or asset testing is required to receive federal cost-shared funds for service delivery to these individuals.

RECOMMENDATION NO. 10

THAT all persons with disabilities be declared "likely to be in need" so that income or needs testing is not required to receive these services.

THAT asset and income restrictions be relaxed so that any person with a disability may access necessary benefits and services he/she may require.

■ Redefining Disability

The present definition of "*handicapped*" is based on a number of out-dated assumptions about persons with disabilities. These assumptions are a form of systemic discrimination, which *a priori* assume and create unemployability and a marginal existence for persons with disabilities. In addition, the complexity of the definition results in a system that is inaccessible and inequitable.

RECOMMENDATION NO. 11

THAT both the provincial and federal governments establish a definition of disability based on the World Health Organization definition, which clearly separates the condition of disability from employment considerations.

- The eligibility process should be based on the self-declaration approach. This approach recognizes the dignity and worth of individuals, and places the responsibility on them for guiding the process.

RECOMMENDATION NO. 12

THAT an efficient eligibility process be established which respects the dignity of the individual and acknowledges the unique and particular needs of each individual.

- The individualized funding service model provides the means by which the extra costs of disability may be met, and at the same time allows for consumers to make their own decisions. Some models of individualized funding have been tested in-B.C. Such approaches are empowering and result in a detailed service plan which better meets personal needs.

RECOMMENDATION NO. 13

THAT the province develop an individualized approach to a person's needs in the areas of goods and services.

■ **RECOMMENDATION NO. 14**

THAT serious consideration be given to the rewriting of the GAIN Act in language that can be understood by those who interpret as well as those who receive the information.



CHAPTER THREE

HOUSING

- I. INTRODUCTION
- II. POLICIES AND PROGRAMS IN
CANADA AND BRITISH COLUMBIA
- III. NEEDS AND GAPS
- IV. SUMMARY: HOUSING FORUM
- V. RECOMMENDATIONS OF THE TASK TEAM

I. INTRODUCTION

Because the Premier's Advisory Council for Persons with Disabilities co-sponsored a Housing Forum with the B.C. Rehabilitation Society in the autumn of 1991, housing was not given in-depth consideration by the Community Services Task Team. Nonetheless, 21 percent of the submissions to the Task Team referred to housing. The input was related specifically to the GAIN program shelter benefits and generally to housing provisions for persons with disabilities in British Columbia.

The Housing Forum addressed concerns and developed strategies related to an increased supply of suitable housing for persons with disabilities; the awareness and understanding of special needs and the market demand for housing of individuals with disabilities; barriers in the design, funding and development of suitable housing; and overcoming the present and future barriers in housing. A summary of the Housing Forum proceedings is included with this report. The Premier's Advisory Council will pursue implementation of the outcome strategies to increase the supply of accessible, affordable housing in conjunction with a Task Force made up of concerned participants from the Housing Forum.

II. POLICIES AND PROGRAMS IN CANADA AND BRITISH COLUMBIA

CANADA

The G. Allan Roeher Institute (1990) published a report which describes major sources of funding for housing and related services and analyses the problems arising from funding arrangements. The report states that most disability-related housing in Canada is funded with some form of federal contribution under the Canada Mortgage and Housing Corporation, which focuses on funding the construction aspects of housing, and/or the Canada Assistance Plan, under which shared funding for shelter allowances is available.

Some provinces have initiated programs even when cost-sharing is not available. The Ontario Ministry of Housing has directed significant funds to non-profit housing programs in response to a severe shortage of affordable housing in particular areas of the province.

BRITISH COLUMBIA

As the provincial agency responsible for social housing, the B.C. Housing Management Commission (Ministry of Municipal Affairs, Recreation and Housing) provides housing for low-income seniors, families, and people with disabilities. Persons with disabilities over the age of 18 who live in housing managed by the Commission and who are eligible for a recognized disability pension, receive a subsidy limiting their rent contribution to 30 percent of their household's gross income. The B.C. Housing Management Commission also provides capital costs for housing projects for low-income and specialized housing. In addition, it provides a service through its Wheelchair Registry which matches those individuals looking for wheelchair-modified accommodation with those having accessible accommodation available for rent or purchase.

The GAIN program provides financial support for a person's shelter/housing needs. GAIN program recipients are eligible for a shelter allowance up to a maximum amount. The maximum amount is the same for all categories of eligibility and varies with family size. For each designated "*handicapped*" person in the family, there is a minimum \$75 shelter allowance.

The Ministry of Health and Ministry of Municipal Affairs, Recreation and Housing both provide housing for persons with disabilities in British Columbia. The Ministry of Municipal Affairs, Recreation and Housing, under the "Community Residences Program", negotiates with private contractors to provide residential care services for adults with mental handicaps. These community based resources range from family homes to small group living situations, and include semi-independent living programs, bed subsidy or proprietary homes, and intensive temporary care facilities for people with mental handicaps and severe behaviour problems.

The Ministry of Health provides for the funding and development of a variety of community-based housing options for adults with multiple handicaps, including some who have previously lived in institutional settings. Typically, these are modified family-style homes operated by societies which are under contract to the Ministry of Health, where two, three, or four people live with assistance from paid staff members, friends, and advocates.

In recent years, Canada Mortgage and Housing Corporation, the Ministry of Health and the B.C. Housing Management Commission (Ministry of Municipal Affairs, Recreation and Housing) have been encouraged by consumers to develop integrated, independent living residences for children and adults with a wide range of disabilities. In the few that have been developed, twenty-four-hour attendant services are provided for those who require them.

The Ministries of Health and Municipal Affairs, Recreation and Housing consider these types of options experimental. Those residing in these units consider them to be extremely successful.

Some specialized long-term care and transitional homes are available for persons with head injuries through the Ministry of Health. Individuals eligible for the program are those who have a traumatic brain injury and are 19 years of age or over.

The Ministry of Health additionally provides licensed residential care facilities and emergency shelter for people with mental illness. The Ministry also funds support workers in specialized housing and outreach workers for mentally ill individuals in market housing.

III. NEEDS AND GAPS

Many submissions stressed the inadequacy of the shelter allowance provisions in the GAIN Program; it is not uncommon for persons with disabilities to spend 50 — 65 percent of their monthly GAIN income on housing. In addition, the only available housing is often unsuitable and run down. Many people with disabilities cannot afford to live alone.

The absence of a shelter allowance for adults living at home or with relatives was identified as a serious gap. The housing costs of the person with a disability are expected to be absorbed by parents or relatives. However, an adult living with non-relatives is eligible for a housing allowance if eligible for GAIN. The SPARC report (1990), examined the costs of daily living compared to income assistance rates and concluded that the major problem for income assistance recipients is access to affordable housing. The Lower Mainland and Victoria regions of the province have the highest proportion of income assistance recipients whose shelter costs exceed the maximum shelter allowance.

The findings from the SPARC study suggest that a special shelter allowance ceiling be established for people residing in regions experiencing significant housing problems. In addition, the findings indicate the need for an increase in the maximum shelter allowance for all income assistance recipients in British Columbia. These findings are supported by a Canadian study on disability-related housing. **Poor Places** (The G. Allan Roeher Institute, 1990) found that more than 50 percent of those surveyed were paying more than the maximum amounts allowed for shelter and utilities.

This study suggests that shelter subsidies should allow actual shelter expenses to be reimbursed up to an established ceiling based on the average cost of shelter in the community where the person lives. An additional subsidy should be provided in those regions with substantially higher shelter costs. In addition, **Poor Places** recommends that there must be increased government support for the supply side of the affordable housing market, including non-profit and cooperative housing.

Submissions to the Community Services Task Team continually stressed the need for available and appropriate housing, based on the rationale that appropriate housing enhances personal autonomy and increases independence. Persons may be hospitalized for significantly longer periods of time because of lack of appropriate housing in the community.

Often the only option available is an inappropriate one. For example, persons with head injuries are housed with people who are mentally ill, or people with multiple sclerosis are housed in geriatric facilities. Available housing should be both need- and age-specific.

A recurring theme throughout the submissions was the absence of residences for adults with disabilities living at home but wanting to move, and adults moving from institutions. The focus and priority given to deinstitutionalization has resulted in the neglect of individuals who have never lived in an institution. This inequity needs to be addressed. In instances where the person lives at home, parents and families want to plan for the move from home before a crisis takes place. These families also need support and respite while their son or daughter is living at home.

The submissions also noted that although an individual's needs did not change, the transition to adulthood was accompanied by a drastic decrease in the amount of care, resulting in some individuals being sent to institutions after turning age 19.

The lack of available resources was stated to be partly caused by zoning issues and public education. Finding an appropriate location for community residences was difficult due to barriers of zoning restrictions and a lack of community acceptance.

Poor Places also found that the shortage of affordable housing for individuals with disabilities is compounded by their need for accessible as well as affordable housing. "Accessible" must apply not only to the physical and structural components of housing, but also to the availability of support services, and proximity to public transportation, schools, vocational programs, employment, recreation and other required services. The shortage of low-cost housing has become more acute in recent years in Canada, generally as a result of economic and social factors. These include the escalating cost of land and housing, particularly in urban areas, and the lack of response to the deinstitutionalization of people with mental handicaps and persons in psychiatric and other hospitals.

Recent announcements regarding housing are that the amount of funding the federal government provides for cost-shared housing programs has been cut back, and that in British Columbia, no new co-op housing programs will be funded this year.

IV. SUMMARY: HOUSING FORUM

In September of 1991, The Premier's Advisory Council for Persons with Disabilities and the B.C. Rehabilitation Society sponsored a Housing Forum to address concerns with accessible housing for persons with disabilities in B.C. The participants were from the consumer population, from organizations representing consumers, government policy makers, funding bodies, architects, developers, service providers, and academics. It was agreed that truly accessible housing includes not only physical and structural accessibility, but also availability of attendant services and proximity to other community supports.

Following the Housing Forum, an Implementation Committee was formed to look at mechanisms for implementing the outcomes. This group, in partnership with the Premier's Advisory Council, is made up of key players in the provision of accessible housing. The committee will be assisted by working groups from each of the four target areas addressed at the forum:

- Regulation/Policy/Design
- Financing/Funding
- Support Services
- Marketing/Awareness

The Housing Forum discussions in the area of regulation, policy and design identified the need for interministerial coordination and administrative streamlining in the provision of accessible housing based on the plethora of programs provided by different ministries. Other issues included the need for adaptive design as part of architectural training, the need to advocate for universal mandatory design standards, and the need for zoning and development incentives to encourage the creation of more housing for people with disabilities.

In the second target area, financing and funding, more than twelve financing options were formulated as suggestions to aid in the provision of more affordable, appropriate, adaptable housing. In addition, it was suggested that the B.C. Housing Management Commission's subsidy programs be simplified and consolidated to better address consumer needs.

Most of the issues and suggested solutions in the area of support services are presented in the Support Services and Long Term Care section of this report. Along with stressing the inclusion of support services in the development of housing policies, other issues identified at the Forum included a long range plan for the delivery of support services to persons with disabilities based on consumer-identified needs and direction, the reallocation of institutional dollars to the delivery of community-based services, and the revision of current Long Term Care assessments based on an individual's actual support needs.

The Marketing and Awareness group recommended the formation of an ongoing Task Force made up of concerned Forum planners, participants and others to oversee the implementation of Housing Forum outcomes. They also presented the concept of "Lifecycle Adaptable Housing". The strategies for marketing the outcomes of the Forum include targeting the home building industry for the promotion of lifecycle adaptable housing, and developing a province-wide marketing strategy to promote empowered consumers and positive lifestyles for persons with disabilities.

A number of themes recurred throughout the issue and strategy discussions. The need for public education around accessible housing was one. That all housing and support service initiatives have consumer expectations and needs as the driving force in all stages of the process was another common concern. Forum participants also agreed on the importance of all concerned groups and individuals working together in a coordinated effort to see that the suggested solutions identified are implemented. Because so many of the issues are consistent with the information from research and presentations to the Community Services Task Team, both groups are working together on the development of recommendations and implementation strategies.

V. RECOMMENDATIONS OF THE TASK TEAM

The Community Services Task Team supports the findings of the Housing Forum and will continue to work toward implementation of the outcomes. Following are four recommendations developed primarily from presentations and submissions to the Task Team. Recommendations 1 and 2 were echoed throughout the proceedings of the Housing Forum.

- Appropriate housing enhances personal autonomy and increases independence. Truly accessible housing includes physical and structural access as well as the availability of support services and proximity to other essential community supports. Due to poverty, lack of accessible, subsidized housing and an inefficient deinstitutionalization process, many people with disabilities live in inappropriate accommodation which does not adequately meet their basic needs. Policies and community housing facilities need to be developed to support the successful integration of persons with disabilities in the community.

RECOMMENDATION NO. 15

THAT the provincial government, in conjunction with federal and municipal governments, take steps to increase the supply of affordable, accessible housing.

- There exists within the Ministries of Health and Social Services a vast number of varied residential programs. Poorly defined responsibilities result in gaps, overlaps and consequently lack of expediency in the provision of appropriate, affordable housing. Housing dollars and dollars to fund support services are also managed by different ministries.

RECOMMENDATION NO. 16

THAT all housing programs provided by government be reviewed and streamlined and that one ministry have the responsibility for housing and housing-related services.

- Persons with disabilities in B.C., many of whom live on limited disability incomes, often spend up to 50 percent of their income on shelter.

RECOMMENDATION NO. 17

THAT shelter allowances be raised to allow actual shelter expenses to be reimbursed up to an established ceiling based on average cost of rental accommodation in the community where the person resides.

- In the present system serious gaps in services exist in a person's transition to adulthood, including lack of residential services and respite support for adults who chose to continue to live in their family home.

RECOMMENDATION NO. 18

THAT residential services, supports, shelter allowances and adequate respite be provided to parents with dependent adults living at home.

CHAPTER FOUR

TRANSPORTATION

- I. INTRODUCTION**
- II. POLICIES AND PROGRAMS IN
CANADA AND BRITISH COLUMBIA**
- III. NEEDS AND GAPS**
- IV. RECOMMENDATIONS OF THE TASK TEAM**

I. INTRODUCTION

The submissions to the Community Services Task Team emphasized that transportation services are essential for the participation of persons with disabilities in society. Twenty-two percent of the submissions referred to concerns with transportation.

The human rights dimension has called attention to discrimination in transit services. The principle of "equal results" is enshrined in the Equality section of the Canadian Charter of Rights and Freedoms. This principle has been interpreted by the courts to mean that public services must be designed to ensure that all citizens, regardless of factors such as race, ethnic origin, age, sex, religion, or physical or mental disability, have equal use (results) of these services. In other words, government must take whatever measures are necessary, including provision for possible additional costs among others, to ensure that access to and use of public services are the same for all groups. The unequal provision of transportation services violates this principle and constitutes discrimination.

Despite some recent progress, persons with disabilities still have their opportunities for employment, education, social life, and even choice of neighbourhood severely curtailed because accessible transportation is insufficient. The lack of equal transportation services for persons with disabilities is a tangible barrier to the integration and participation of persons with disabilities in our communities.

Several organizations in British Columbia are currently advocating for improved transportation for persons with disabilities. The Committee to Promote Accessible Conventional Transit (COMPACT), composed of a number of individuals belonging to major disability organizations in this province, believes that an accessible public transit system is essential to meet the needs and equality goals of the population with disabilities in British Columbia.

A second example is the Task Force on Transportation of the B.C. Coalition of People with Disabilities which forwarded recommendations on transportation needs in British Columbia after a series of community hearings (1989). The Task Force is currently drafting a Provincial Transportation Code.

The Premier's Advisory Council is concentrating its efforts on the establishment of an integrated multi-modal province-wide transportation network which provides full and equal access to persons with disabilities. This goal is being pursued through a review of policy with BC Transit and through a Transportation Sub-Committee focusing on the role of accessible taxi service.

As a result of this initiative, BC Transit has embarked on a province-wide planning program for fully accessible transit systems. Plans will be prepared by early 1993 to make each transit system in the province accessible to persons with mobility impairments.

II. POLICIES AND PROGRAMS IN CANADA AND BRITISH COLUMBIA

CANADA

The federal government has jurisdiction over interprovincial and some intercity modes of transportation, including air and rail travel. Through Transport Canada's Transportation of Disabled Persons' Directorate, the federal government also undertakes some testing, research and development of accessible vehicles. Ferries, intercity buses and local transit systems, however, come under provincial authority in most provinces.

Most municipalities across Canada offer some form of subsidized parallel transportation service for persons with disabilities who cannot access standard transit vehicles and systems. Most parallel systems in place share common problems: growing demand, higher fares, discriminatory service based on degree and type of disability, and limited hours of service. In British Columbia, these problems are further complicated by the geographic nature of the province, with rural centres spread out over an immense area. The majority of new initiatives continue to take place in the Lower Mainland, and it will take some time, years in some instances, before the rest of the province can take advantage of new developments such as lift-equipped transit buses.

REVENUE CANADA - Gasoline Tax Rebate

The federal government allows a tax rebate on gasoline for people with disabilities, provided the applicant is not able to use public transportation. Forms are available at post offices and a medical certificate is required. The rebate currently stands at about one and a half cents a litre. Receipts are required upon request.

BRITISH COLUMBIA

BC Transit operates public transportation systems which are available to the general public in most areas of British Columbia. Hours of operation and levels and costs of service are determined locally and vary considerably across the province. In the larger municipalities, service is available seven days per week; in the largest service area, the Lower Mainland, service is available 22 hours a day on some lines.

Service costs vary, but are generally between \$.70 and \$1.35 for a one-way ride; daily and monthly discount passes are available. In addition, many municipalities offer further discounts, called concession fares, for seniors, students and persons with disabilities, among others. These concession rates are available for regular one-way fares, day passes and monthly fare cards.

Until recently, many persons with disabilities and persons who are elderly were unable to use the standard public transportation system because of stairs leading into the vehicles. A plan to replace the standard transportation fleet with lift-equipped vehicles has recently been implemented in the Lower Mainland: all new conventional transit vehicles will be purchased with lifts so that the standard Lower Mainland transit fleet will be fully accessible by the year 2006.

BC TRANSIT — handyDART

Independent organizations are contracted by BC Transit to provide door-to-door transportation for anyone unable to use regular public transit. Service decisions are made locally, in conjunction with decisions about conventional transit. In general, days and hours of service are lower on handyDART than on conventional transit systems in the same area.

The fare structure is also decided locally and varies in each community. However, with the exception of Vancouver, handyDART fares are usually higher than the cost of riding the conventional bus system. Concession fares, day passes, monthly fare saver passes and annual transit passes for persons with disabilities are not available to handyDART users, with one exception: Vancouver honours the regular monthly fare card on handyDART vehicles, but not the discount monthly fare card (concession rate). A similar pattern prevails in Victoria where a special monthly pass of \$50 is honoured, but not the regular (\$40) or the discount monthly passes (\$25).

BC TRANSIT - BUS PASSES

A one-year (January 1 - December 31) unlimited use bus pass is available for \$39 (1991 rate) to those people receiving benefits from the Ministry of Social Services or to individuals in institutions who have been designated "handicapped" by the Income Assistance Division. This pass can only be used on the standard transit system and not on handyDART vehicles. This pass is not available to low-income persons with disabilities who receive income from other sources such as employment or federal pension. There is no reduction in fee for a partial year's usage.

BRITISH COLUMBIA FERRY CORPORATION — Subsidized Fares

Half-price fare for persons with disabilities and attendants is available for persons possessing a B.C. Ferry Corporation I.D. card or acceptable proof of disability.

B.C. MINISTRY OF FINANCE — Provincial Gasoline Rebates

People unable to use public transportation because of a disability are eligible for a provincial gas rebate from the Ministry's Consumer Taxation Branch. Application forms are available from the Branch; they must be returned with a doctor's verification of the disability along with photocopies of vehicle registration. The car must be registered in the name of the person with the disability to be eligible. Receipts must be retained and submitted with the claim. The amount of the rebate is the tax paid on the purchase of fuel.

Effective August 1, 1991, persons with disabilities who are unable to drive their own vehicle are eligible for the rebate. Effective the same date, the amount of tax that is refundable is limited to \$200 per person each year, calculated from August 1 to July 31.

GAIN TRANSPORTATION ALLOWANCE

Under the Ministry of Social Service's income assistance program, GAIN, expenses for transportation may be covered as an additional benefit to persons with disabilities.

TRANSPORTATION FOR MEDICAL PURPOSES

Transportation and accommodation can be provided to persons eligible for Ministry of Social Services' sponsored medical coverage, in order for them to obtain necessary medical treatment. This is provided only when considered essential. A person is expected to explore all other resources such as assistance from relatives, volunteer drivers, etc., before requesting this service from the Ministry of Social Services. Financial eligibility is determined. The following types of medical transportation may be authorized as appropriate:

- Public Transportation — e.g. local bus service.
- Community Transportation Services — e.g. handyDART, Easter Seal bus, etc.
- Taxis — Use of taxis can only be considered in cases where the person's medical condition precludes the use of public transportation and community transportation services are not available.

INSURANCE CORPORATION OF B.C. — Handicapped Driver Discount

Drivers and owners of personal vehicles, who have disabilities and who qualify, may receive 25 percent off the cost of basic, compulsory Autoplan coverage. The registered owner or lessee of a vehicle is eligible if he or she is the principal owner and is *handicapped* as defined under the Motor Fuel Tax Act. The *Handicapped Driver Discount* can only be applied to one vehicle. Proof of disability may be established by one of the following documents:

- a letter from a doctor indicating that the person is permanently dependent on a wheelchair or has suffered permanent impairment of locomotion or has suffered complete and permanent functional loss of the lower limbs;
- a letter from the Ministry of Social Services indicating that the person is receiving benefits as a person with disabilities; or
- a letter from the Workers' Compensation Board (or other agency) indicating that the person is receiving a disability pension.

III. NEEDS AND GAPS

The submissions made to the Community Services Task Team expressed concern about the absence of a fully integrated multi-modal transportation system for all persons in the province.

Accessible, safe and dignified modes of transportation are the key links required to bring together the various elements of a truly integrated community. For purposes of employment, volunteer work, shopping, medical appointments, recreational opportunities or visiting family and friends, among others, transportation is often the missing link in such endeavours. For those who cannot access the standard transit vehicles used in most communities, the alternatives are quite limited in meeting the day-to-day needs of persons with disabilities.

The inadequacy of the GAIN Program transportation allowance was repeatedly reported in the submissions. In addition, only persons receiving GAIN for Handicapped benefits are eligible for bus passes. These restrictive criteria exclude other persons with disabilities.

Regional disparities were a recurring theme throughout the submissions. Many respondents reported a lack of transportation services in smaller communities. Those who had access to transportation indicated that the hours of service frequently did not correspond with their needs. Heavy demand on the service was another factor in the availability of the service.

An increasing demand for transportation service and the inability to keep up with the demand has resulted in a system which is "forced" to abide by rigid scheduling and policies in order to at least meet some needs. The persons who currently benefit from this service are those with fixed schedules, those able to book in advance, those living in larger communities, and those able to adhere to a driver's schedule. Those persons whose schedules change from day to day, often as a result of their disability, may be left to fend for themselves. High priority transportation needs that cannot be planned in advance, such as job interviews and medical emergencies, are often not met. The lack of adequate transportation is a hidden and effective barrier to the participation of persons with disabilities in employment, access to medical care, education and participation in the community.

The need for transportation in rural areas can be as critical as in larger urban areas. The costs to the individual to provide his or her own transportation are often prohibitive, especially for GAIN recipients.

Accessible parking was also noted as a component of a transportation network. Designated parking for persons with disabilities is often abused. For people who use their own vehicles, being able to park in a safe and appropriate place can be the difference between continuing the day's activities or cancelling such expectations.

Persons receiving Canada Pension Plan benefits or who are not eligible for GAIN benefits, do not receive assistance for their transportation needs. The standard cost of monthly bus passes available to the general public is beyond the means of many persons with disabilities. Bus passes and discount rates available on the conventional bus system are not available on handyDART.

IV. RECOMMENDATIONS OF THE TASK TEAM

- The level of public transportation service available to persons with disabilities in British Columbia is significantly lower than that provided to persons without disabilities. This violates the equality rights of persons with disabilities and is an effective barrier to the participation of persons with disabilities in the community.

RECOMMENDATION NO. 19

THAT a coordinated multimodal transportation system providing equal transportation service to persons with disabilities be developed, with accessible conventional buses, parallel vehicles, taxis, and accessible ferries.

THAT BC Transit provide increased and more flexible funding for handyDART service.

THAT BC Transit increase handyDART vehicle fleets, extend hours of service, make greater use of taxi back-ups throughout the province and develop uniform standards of service.

THAT all ride requests for handyDART be met, as is the case with the conventional transit system.

THAT the hours and days of service provided by handyDART in a community be the same as the hours and days of service of the conventional transit system in the same community.

- Because of limited rides currently available on handyDART, a priority system for ride requests is in place. This priority system violates the privacy and equality rights of persons with disabilities.

RECOMMENDATION NO. 20

THAT the priority system for rides on handyDART be eliminated.

- In the present transportation network, regional disparity and varying standards of service, especially among rural and small urban centres, continue to serve as barriers to equality of service for persons with disabilities.

RECOMMENDATION NO. 21

THAT the province-wide planning program for a fully accessible transportation system, as announced by BC Transit, address the issues of regional disparity, varying standards of service and appropriate service in rural areas.

■ **BUS PASSES AND DISCOUNT RATES**

A variety of bus passes and discount rates are available to users of the conventional transit system. Those who rely on handyDART, however, are excluded from using such passes on the handyDART system.

RECOMMENDATION NO. 22

THAT all bus passes and discount rates available to users of the conventional transit system be made available to handyDART users throughout the province.

- An annual bus pass is available for use on the conventional transit system, but only for persons who qualify for GAIN benefits. Persons with disabilities with low income from other sources, such as Canada Pension Plan or employment, cannot purchase these passes. If these passes were available to any person with a disability, a maximum income cutoff could be established along the lines of the Medical Services Plan subsidy available for low-income persons.

RECOMMENDATION NO. 23

THAT the annual bus pass, now available to GAIN recipients, be made available to all low-income persons with disabilities wherever transit services are available to the general public throughout the province.

■ **GAIN TRANSPORTATION ALLOWANCES**

Persons eligible for GAIN benefits may receive some assistance to meet transportation expenses, but the level of support is inadequate.

RECOMMENDATION NO. 24

THAT GAIN transportation allowances be increased to reflect accurately the transportation costs to the individual.

■ **ACCESSIBLE TAXI SERVICE**

Accessible taxi service represents the vital link in an integrated multi-modal transportation network. Some effort has been made, mostly in the Lower Mainland, to use accessible taxis through BC Transit's Taxi Supplement Program and Scrip System (Taxi Saver Program) for handyDART users as an alternative during peak periods and to help meet overloads.

RECOMMENDATION NO. 25

THAT the use of BC Transit's Scrip System Taxi Saver Program be expanded to include smaller and more rural communities throughout the province.

- Many low-income persons with disabilities still cannot afford to participate in the Taxi Scrip Program.

RECOMMENDATION NO. 26

THAT an additional discount rate for the Taxi Scrip Program be made available to all persons with disabilities with low income.

- Taxi owners and operators may be hesitant to commit to the purchase and conversion of vehicles because of the costs involved.

RECOMMENDATION NO. 27

THAT the provincial government provide financial support to taxi owners for the conversion of vehicles to meet the accepted standards for accessible taxis.

■ **PERSONAL VEHICLES IN RURAL AND REMOTE AREAS**

In rural and remote areas of the province where there is no existing transit service, it is essential that persons with disabilities who are receiving social assistance or who have a limited income be able to access services such as medical, shopping, equipment and repairs which are usually located in rural centres.

RECOMMENDATION NO. 28

THAT assistance be provided for the purchase, maintenance and insurance requirements for personal, private, accessible vehicles of persons with disabilities who are excluded from existing transportation services because of where they live or other circumstances, such as low income.

CHAPTER FIVE

**MEDICAL SERVICES, TECHNICAL AIDS,
EQUIPMENT AND SUPPLIES**

- I. INTRODUCTION**
- II. POLICIES AND PROGRAMS IN
CANADA AND BRITISH COLUMBIA**
- III. NEEDS AND GAPS**
- IV. RECOMMENDATIONS OF THE TASK TEAM**

I. INTRODUCTION

A significant percentage, 35 percent, of the submissions gave input on issues concerning policy and programs for the provision of medical services, technical aids, equipment and supplies.

In the 1986 Census, 41 percent of adults (aged 15 to 64) with disabilities living in households in British Columbia reported out-of-pocket expenses not reimbursed by any insurance or government program. The types of non-reimbursed expenses reported were: prescription/non-prescription drugs, special clothing, aids and equipment, non-insured medical services, transportation, personal services and other.

Medical services, technical aids, equipment and supplies are provided to persons with disabilities mainly by three Ministries in British Columbia: Advanced Education, Training and Technology; Health; and Social Services.

Two significant reports on the subject of technical aids, equipment and supplies for persons with disabilities have been commissioned by the government in British Columbia in recent years:

In March of 1987, the Ministry of Health released a document entitled "*A Report on the Provision of Medical Equipment and Supplies to the Chronically Ill and Disabled Population of British Columbia.*"

This study identified six basic problems:

inequities in the benefits available to various groups; service fragmentation; poor communication with the public and between helping professionals; barriers to accessing services; varying assessment skills; product knowledge on the part of therapists; and centralization of specialty health services and medical/surgical suppliers.

In 1988, the provincial government funded a study to develop a strategy for service delivery that would address problems with the availability of effective augmentative communication and rehabilitation technology services in British Columbia. To date this report, entitled "*Technology for People with Disabilities, An Implementation Strategy for British Columbia,*" 1989, has not been widely released nor has implementation been realized. This statement made in the report is echoed in the submissions we received:

Developments in the field of rehabilitation technology have given many people with disabilities hope for a more independent and productive life. In British Columbia, this technology is not yet available to many who could benefit tremendously from its use.

Efforts on a number of fronts over the recent years have made clear what the issues in this area are. The submissions reported the same issues. The development of strategies for addressing them is now required in British Columbia.

II. POLICIES AND PROGRAMS IN CANADA AND BRITISH COLUMBIA

CANADA

The Federal Government has legislation which establishes cost sharing programs which assist provinces in providing medical services, technical aids, equipment and supplies to persons with disabilities. Examples of this legislation include: the Established Program Financing Act, the Canada Assistance Plan and the Vocational Rehabilitation for Disabled Persons Act.

There is great variation among the provinces in their provision of medical services, technical aids, equipment and supplies. There are programs available in other provinces which are not available in British Columbia.

Some of the literature recommends that income assistance and social services be separated in national policy to ensure that people's needs for assistance outside basic income are more clearly assessed and met. For example, the G. Allan Roeher Institute (1988) study states that a positive feature of some provincial income support systems is the recognition that recipients who are disabled require extra financial help to offset the high costs of the goods and services they need. This help is given in the provisions for special assistance items such as medication, prosthetic devices and technical aids.

The extra costs that persons with disabilities incur are recognized and reduced by federal income tax credits for some medical- and disability-related expenses; many alternative therapies and medicines prescribed by physicians are not eligible for tax credits. As well, because medical expenses must first be subtracted from a percentage of income, this means that medical expenses must be high before one can receive tax credits.

BRITISH COLUMBIA

MEDICAL SERVICES PLAN (MSP)

The Medical Services Plan (MSP) is a government run medical insurance plan in B.C. (Ministry of Health). The medical services of physicians and certified specialists are covered under the plan. MSP provides coverage for physiotherapy, chiropractic, naturopathic and massage therapy to a maximum of 12 visits per year for persons under age 65; the limit is 15 visits for persons over 65. The current user fee (1991) is \$5. Podiatry, optometry and orthoptic services are also available on a limited basis.

Premiums for this medical coverage are paid by the Ministry of Social Services for adults with disabilities who are receiving GAIN for Handicapped benefits. This coverage is also available to persons with disabilities who are employed and who were previously in receipt of GAIN for Handicapped benefits.

The Ministry of Social Services also provides medical goods and supplies to persons on GAIN or who are designated handicapped. Financial eligibility is determined by a person's ability to contribute to costs. Coverage is generally not available to persons not in receipt of GAIN, although exceptions can be made.

Requests for equipment and supplies must come from a health-care professional and must be approved before purchase. Consideration may be given only to essential medical needs: that is, to equipment or supplies which prevent medical or health deterioration, or to mobility aids (e.g. wheelchairs, canes). The Ministry of Social Services does not provide medical equipment and supplies to individuals residing in facilities funded by the Ministry of Health.

To receive approval for the purchase of equipment through the Ministry of Social Services, a person must first obtain a written prescription including a diagnosis of the medical condition. If the cost of equipment is between \$100 and \$250, the person must submit quotations from at least two medical supply companies. Equipment and supplies over \$250 are approved by the Health Services Division of the Ministry of Social Services who order the supplies and arrange for direct shipment to the person. The Ministry does not accept payment responsibility, except in an emergency.

Equipment repairs may also be funded by the Ministry of Social Services. Repairs under \$250 can be authorized by local offices upon receipt of a quotation on the estimated cost of repairs; repairs over \$250 must be approved in Victoria by the Ministry of Social Services.

Many essential items are not covered by the Ministry of Social Services including: communication aids (telephone, bliss boards); household items/renovations (elevators, ramps, wheelchair lifts, waterbeds); aids to daily living (recreation equipment, special eating utensils); vans and van lifts; vision devices; and vitamins, minerals, and over-the-counter drugs.

Equipment can also be provided through the Vocational Rehabilitation Service of the Ministry of Advanced Education, Training and Technology. This program is designed to enable people with disabilities to pursue employment, but these services can only be provided to persons who will be considered employable after VRS assistance ceases. Restorative goods and services may be provided which alleviate, reduce or remove a disabling condition; which are unavailable to the general public without charge; and which are required by the individual to undertake training or accept employment.

Specialized tools, equipment and clothing may be provided, if necessary, for the individual to undertake vocational training or competitive employment. These would be items of a personal nature, specifically adapted and non-transferable.

Technical aids and equipment (transferable goods) such as optacons, visualtecs, recording equipment and microcomputers may also be available.

Workplace modifications not exceeding \$15,000 which enable an individual to enter, resume or maintain competitive employment can also be considered upon receiving a written plan from the employer. Vehicle modifications may be available for funding up to \$10,000, if the modification is necessary for training or employment and if the individual cannot use public transportation.

In addition, equipment to enable students with disabilities to access post-secondary education is available through a different program: the Assistance Program for Students with Severe Disabilities (Ministry of Advanced Education, Training and Technology).

DENTAL CARE SERVICES

Dental services are provided only to persons with valid Ministry-sponsored medical coverage. A maximum amount of \$500 per calendar year is available without prior approval.

PHARMACARE

The Pharmacare government-funded service in British Columbia is administered by the Ministry of Health and provides financial assistance for prescription drugs; insulin, syringes and needles for diabetics; ostomy supplies; and prosthetic appliances. Persons who are on Ministry of Social Services-sponsored medical coverage receive 100 percent coverage.

III. NEEDS AND GAPS

INPUT FROM SUBMISSIONS

The following quotation from one particular submission clearly expresses the sentiments of a number of submissions:

The prescription, provision and proper use of specialized medical equipment or technical aids can make the difference between dependence and independence for many disabled adults. Due to the lack of a universal access program, many persons remain in institutional settings dependent on caregivers for activities they might otherwise be able to perform independently with the proper equipment.

Input on specific issues follows.

B.C. MEDICAL SERVICES

The major problems identified with B.C.'s Medical Services Plan related directly to the lack of coverage for various services which were recognized in the submissions as essential services for persons with disabilities. Coverage for long-term physiotherapy, for example, is available only when someone is in hospital, and not available in the community (the Community Physiotherapy Program provides only limited service).

The five dollar user fee for physiotherapy is unaffordable for many persons with disabilities. This fee can be waived for persons with Ministry of Social Services-sponsored health coverage, persons covered under I.C.B.C., Worker's Compensation, or persons receiving premium assistance for MSP.

Several submissions commented on the need for improved training and education on disabilities for medical personnel.

In addition, submitters noted the absence of sign language interpreting in medical situations for people who are deaf or hard of hearing.

PHARMACARE

Pharmacare provides free coverage for persons receiving income assistance, creating problems for individuals just above assistance levels or persons with high-cost needs who are required to pay the \$375 deductible plus 20 percent of the remaining cost. Many submissions revealed that persons unable to afford these costs often go without, or use inadequate or old items. Persons with repair or maintenance costs are doubly burdened as they are unable to include these costs in the deductible.

The inadequacy of coverage for certain items created further difficulties and costs for some individuals. Orthotics are available for children, not for adults. Recreational or spare prostheses are not covered. People who need essential non-prescription items, such as bandages for pressure sores, over-the-counter drugs, and vitamins for medical purposes are also not eligible for coverage, even if these items are prescribed by a physician.

Current service delivery mechanisms dictate that a client provide at least two estimates for necessary equipment. Several submissions referred to the difficulties this created for some individuals, resulting in this activity often being passed on to the caregiver or a health care professional.

MEDICAL EQUIPMENT AND SUPPLIES

The process for obtaining medical goods and supplies through the Ministry of Social Services was identified in numerous submissions as fragmented, inconsistent and complicated. It is evident that persons who receive the "handicapped" designation at some time in their lives benefit more than those who do not obtain this designation. Persons with incomes above assistance levels, or those not eligible for income assistance, may have disability-related costs which bring them well below assistance levels, but are not eligible for coverage.

A general lack of provision for some items was also identified throughout the submissions. Lack of coverage for items such as communication aids, white canes, high-technology items, incontinence supplies, and transportation equipment were identified; these are essential health care needs for persons with disabilities. For persons with disabilities living outside of metropolitan areas, high travel expenses are incurred in gaining access to specialized or centralized services.

Persons requiring essential equipment can also apply to charitable organizations. However, availability and criteria vary, creating yet another complex and unreliable service system.

Several submissions referred to the risks created for some persons with disabilities who rely on equipment for mobility and health needs, but who are unable to claim reimbursement for unauthorized emergency repairs. As most persons with disabilities rely on limited incomes, it is difficult for them to absorb repair costs; many, therefore, are forced to do without essential equipment until approval for repairs is authorized.

A bureaucratic dispute of some consequence for persons living in Long Term Care facilities was that the Ministries of Health and Social Services do not agree which ministry is responsible for the costs of medical equipment and supplies.

Problems with coverage and inconsistencies were further aggravated by delays in service delivery. Lengthy time delays between the time equipment was ordered and actually received put both individuals and caregivers at risk. Some prescriptions for equipment were sent back to physicians by Ministry of Social Services staff who would question whether cheaper equipment would suffice.

Submissions also indicated delays in reimbursement for supplies. Individuals requested more autonomy by participating in the choice of the equipment distributor. Persons needing medical supplies often preferred to deal with local distributors who were knowledgeable about their needs. The submissions described policies and programs regarding equipment and supplies as fragmented and confusing.

The consequence is that individuals, caregivers and professionals devote an inordinate amount of time searching for equipment that in the last analysis is frequently unavailable or unsatisfactory.

DENTAL BENEFITS (MINISTRY OF SOCIAL SERVICES)

Several submissions referred to the inadequacy of current allowances for dental benefits; the current level of \$500 has remained unchanged since 1988 when it was reduced by 30 percent from \$700. Since then, one submission indicated that rates have increased by approximately 25 percent, further decreasing the benefit for eligible persons.

Due to long delays in receiving reimbursement, and the stated ability to recover only 85 percent of their costs, some dentists are refusing to serve GAIN recipients on a regular basis. This further hinders persons with disabilities from receiving appropriate dental care.

The lack of coverage for speciality items such as crowns, bridges and orthodontic work for adults causes high costs for those persons in need of such services but unable to afford them. Current coverage for dentures, which allows replacement once every five years, was stated to be inadequate and unrealistic for some persons.

IV. RECOMMENDATIONS OF THE TASK TEAM

- The criteria for eligible equipment should be based on need and the adequacy of the equipment in assisting a person in achieving maximum independence.

RECOMMENDATION NO. 29

THAT policy governing the provision of technical aids, equipment and supplies for people with disabilities reflect the principles of universal accessibility for all members of society, regardless of ability to pay, place of residence and/or type of disability.

- The current narrow definition of eligibility for equipment for persons with disabilities does not include many types of equipment and supplies.

RECOMMENDATION NO. 30

THAT criteria for eligible equipment be expanded in consultation with consumers to ensure that all necessary equipment and supplies are available for independent living.

- Too often non-prescription medical needs and supplies cannot be purchased by those persons barely above the poverty level, which means that their medical needs are not adequately provided for.

RECOMMENDATION NO. 31

THAT medical coverage reflect the full range of needs of persons with disabilities, including alternate therapies, non-prescription medical drugs and supplies, as insurable expenses under the B.C. Medical Services Plan and Pharmacare Program.

▣ **RECOMMENDATION NO. 32**

THAT access to information on services and procedures be improved for all persons with disabilities by making them available in alternate formats and in plain language.

- ▣ The communication needs for the deaf and hard of hearing and the deaf blind are not being met in doctor's offices and hospitals.

RECOMMENDATION NO. 33

THAT sign language interpreters for the deaf and hard of hearing and intervenors for the deaf blind be provided in medical situations at no charge to the user.

▣ **RECOMMENDATION NO. 34**

THAT policies in the Ministry of Social Services give increased choice of distributors for purchase of equipment and supplies.

▣ **RECOMMENDATION NO. 35**

THAT assessment for eligibility for medical services, technical aids, equipment and supplies be based on effective results for the person rather than cost.

▣ **RECOMMENDATION NO. 36**

THAT a mechanism be implemented to ensure that policies address equipment maintenance at provincial and/or national standards.

■ **RECOMMENDATION NO. 37**

THAT the service delivery system be reviewed and reorganized so that there are no gaps in equipment delivery and so that persons with disabilities get simple and quick access to equipment; this would include an efficient process for pre-authorization, pre-payment and reimbursement.

- Too often emergency supplies cannot be purchased as recipients of the various income assistance programs do not have the money to prepay and wait for reimbursement.

RECOMMENDATION NO. 38

THAT the provisions for acquiring emergency supplies and repairs be streamlined through an efficient pre-approval system.

- Consideration should be given to the establishment of a loan bank which could effectively utilize equipment presently not in use and could also serve as a short term emergency supply centre, as some equipment may take a long time to supply.

RECOMMENDATION NO. 39

THAT a provincially-coordinated equipment loan program be implemented.

■ **RECOMMENDATION NO. 40**

THAT dental benefits under the Ministry of Social Services be increased and dental coverage be expanded to include all required dental services.

THAT dental coverage be expanded to include all persons with disabilities.

- Although it is recognized that user fees are paid by the Ministry of Health for persons receiving premium assistance, user fees for therapies such as physiotherapy, occupational therapy, speech therapy and others, present a barrier to use by persons with disabilities who fall just above that level of income to be eligible for assistance.

RECOMMENDATION NO. 41

THAT user fees for therapeutic services be eliminated for low-income persons with disabilities.

CHAPTER SIX
SUPPORT SERVICES AND LONG TERM CARE

- I. INTRODUCTION**
- II. POLICIES AND PROGRAMS IN
CANADA AND BRITISH COLUMBIA**
- III. NEEDS AND GAPS**
- IV. RECOMMENDATIONS OF THE TASK TEAM**

**CHART: FOUR SUPPORT PROGRAMS IN B.C.:
A COMPARISON**

I. INTRODUCTION

"Without the accompanying supports, there are really no options for community living" (G. Allen Roeher Institute, 1990).

Next to the GAIN Program, input on Support Services and Long Term Care received the greatest attention in the submissions to the Community Services Task Team. Thirty-nine percent of the submissions commented on issues and options for change in this area of government programs.

Most submissions noted that support services are essential to enable persons with disabilities to participate in the community, and the current system in B.C. is inadequate. The failure to provide adequate and appropriate home and community support services was seen as a hidden but very real barrier to the equal participation of persons with disabilities in the community.

As a result of these concerns, a coalition was formed in British Columbia of persons with disabilities, elderly persons and advocates, to reform the Long Term Care/Continuing Care system in British Columbia. Some of the concerns of this coalition were articulated in a submission to the Royal Commission on Health Care and Costs in November of 1990 and are reflected in this report.

In addition, human rights legislation has implications for the provision and design of support services for persons with disabilities. As noted in the first section of this report, the rights of persons with disabilities are protected by provincial and federal human rights legislation. These protections include the right to privacy and freedom of choice, and the principle of "equality of results", which has been interpreted to mean that government programs must be available to persons with disabilities as they are to the public at large. As will be seen in the ensuing discussion, support services in British Columbia are currently provided in ways which violate many of these principles. Substantial reform is needed so that the service delivery system meets the needs of persons with disabilities and is consistent with these basic rights and principles.

In addition to the human rights dimension, a theme which was repeated in many submissions was the importance of providing a full range of services to support all the activities of community life: employment, education, recreation, family and community life. However, most of the support programs currently providing services in British Columbia provide only parts of this range of needed services — some of these services are called attendant services, others are called homemaker programs, and others are called day programs. Because we see these separate programs as providing segments of what is really one system of essential support services, we have considered these services together in this report, even though their stated purposes and service names may be different. For the purposes of this report, we have defined these services to include non-medical assistance provided by an individual to a person with a disability to enable that person to participate in the community: this includes assistance in activities of household management, personal care, employment, education, recreation, family and other community activities. When medical activities can be more appropriately delivered within this model, such as an attendant providing range of motion or catheter care, they are included in our definition. To facilitate discussion in this report, we have used the term *support services* to describe this essential range of needed services.

II. POLICIES AND PROGRAMS IN CANADA AND BRITISH COLUMBIA

CANADA

All provinces in Canada currently provide some form of support service to persons with disabilities. However, the manner in which services are delivered, and the amount and type of service available, varies widely. Most provinces deliver these programs through home care or homemaker agencies, but Manitoba and Alberta are operating pilot programs to provide funds directly to persons with disabilities, who then coordinate their own individualized support programs.

Some provinces, such as Quebec and Manitoba, provide support services on a universal basis, whereby services are provided at no cost to all persons with disabilities. Other provinces, such as British Columbia and the Atlantic provinces, provide these services on a residual basis, that is, as a last resort after all other family and community resources have been explored. A fee for service is charged for those whose incomes are above a certain preset level.

A recent change in the federal/provincial agreements governing federal/provincial cost-sharing arrangements allows provinces to declare persons with disabilities as "likely to be in need", so that services can be provided on a universal basis under CAP (federal/provincial cost-sharing) funded programs. As a result of this decision, Alberta and Nova Scotia have modified their assessment procedures and are providing these services at no cost on a universal basis to persons with disabilities. British Columbia has not yet considered this option.

BRITISH COLUMBIA

In British Columbia, support services are provided through eight different programs operating out of three different ministries: The Long Term Care Homemaker Program (Ministry of Health); the Family Support Homemaker Program (Ministry of Social Services); Day Programs for multiply handicapped persons (Ministry of Health/Services to the Handicapped Branch); the Assistance Program for Students with Severe Disabilities (Ministry of Advanced Education, Training and Technology); Supported Work Program for persons with mental handicaps (Ministry of Social Services); Supported Work Programs and Community Living Support Programs for persons with mental health problems (Ministry of Health); and Life Skills Programs for head injured persons (Ministry of Health).

Each program has evolved independently: crucial aspects of service delivery, such as eligibility criteria, availability of information, appeal procedures, amount and type of service available, and client control vary widely. Furthermore, the two largest programs — the Ministry of Health's Long Term Care Homemaker Program and the Ministry of Social Services's Family Support Homemaker Program — were not developed to meet the needs of individuals with disabilities, but were designed to provide assistance to seniors or children. Although these services have expanded to include persons with disabilities, their original design has had a significant impact on the underlying philosophy, eligibility, administrative procedures, and type and amount of service that is provided. None of these programs is provided on a universal basis, income or needs testing is required, and user fees are assessed for the two largest services.

Although these services have evolved independently, they are actually part of the same service continuum. To facilitate comparison and demonstrate the complexity of the service delivery system, we have included a chart summarizing four of these services at the end of this chapter. However, because the majority of feedback we received concerned the Ministry of Health's Long Term Care Homemaker Program and because this service constitutes the largest service delivery system, we have included a detailed description of this service in the text of this report.

Long Term Care Homemaker Program

Description of Program

The Long Term Care Homemaker Program provides homemaking/attendant support services in the home to adults (over 19) with a chronic illness or condition lasting more than three months. Service is provided to seniors, persons with physical disabilities, and persons with mental health impairments whose condition is primarily physical. Persons with primarily mental health conditions usually receive service through the Mental Health Division, although in some areas of the province they receive service directly from Long Term Care. Persons with mental handicaps receive service through the Ministry of Social Services's Family Support Homemaker Program, unless their condition is primarily physical. Service is provided only in the home; no assistance to support work, education, recreation or raising a family is provided.

The Long Term Care Homemaker Program is part of a larger array of services provided by the Continuing Care Division of the Ministry of Health. Other services include services in the community (Adult Day Care) and residential services (Intermediate and Extended Care Facilities). A description of these other services is not included in this report.

Assessment

The amount of assistance provided, fee for service, and agency providing the service are determined by a Long Term Care Assessor, usually operating out of a municipal or provincial health unit. Assessments for persons with mental health impairments are sometimes completed by mental health services staff, in some, but not all, areas of the province. The criteria used to assess persons with psychiatric disabilities are the same as those used to assess other client groups such as seniors or persons with physical disabilities. The amount of assistance provided depends on two factors: availability of assistance from family, friends or community organizations; and level of care as determined by Long Term Care criteria.

Long Term Care Assessors determine the amount of assistance by assigning the client to one of three categories of care; each category has a predetermined limit on the amount of service available: personal care (up to 48 hours/month), intermediate care (up to 98 hours/month) or extended care (up to 120 hours/month). The criteria to determine assignment to these three levels are predetermined and are the same as those used to determine levels of institutional care: persons must need professional or nursing care/supervision to be assessed for intermediate care; persons must be unable to transfer independently and be unable to walk more than 10-15 steps to qualify for the extended care level of service. The Long Term Care policy manual states that assessments must be made using these criteria, and "not on the basis of perceived service needs."

Assignment of specific amounts of service (within the person's level of care) is made according to over 70 criteria, which include reference to the person's emotional state, physical ability and possible need for supervision; these criteria are complex and subject to interpretation. Long Term Care Assessors also use a 5-page assessment form which catalogs the abilities/limitations of the prospective client. This form includes the assessor's comments on the client's personal habits (including whether the client smokes or drinks and whether the assessor believes these habits are a problem), appearance, attitude, mental state and capacity, and a variety of other attributes including the client's ability to perform household and personal tasks.

Assessments can exceed the maximum 120 hours per month, but this is rarely done, and these exceptions require the consent of the unit supervisor and written notification to the head office in Victoria.

Cost to the User

Homemaker/Attendant services provided by the Ministry of Health are available to all eligible individuals, regardless of income. However, fees are charged for homemaker services depending on the income of the applicant, based on a sliding scale with exemptions for disability (\$125), employment (\$100) and general living expenses (\$618). Medical expenses are not deducted, and larger employment or disability expenses cannot be itemized and deducted. All spousal income is considered part of the financial assessment after allowing for an additional exemption (\$319); earned spousal income may be exempted from this assessment if the person is designated as handicapped by the Ministry of Social Services (to obtain this designation, the person must qualify for GAIN for handicapped; please see the Chapter on Income Support for more details). After deducting allowable exemptions, the applicant's remaining net income is divided by 2 and then by 30 to derive a daily fee for service: based on this formula, a person who needs assistance seven days per week remits a fee seven times higher than an individual requiring assistance one day per week. A working disabled person who needs assistance seven days a week would pay half of her/his remaining net income for homemaker/attendant service, after deducting the maximum \$843 deduction.

Provision of Service: Choice of Agency, Worker, Consumer Control

Homemaker/attendant service is provided by homemaking agencies which contract with Long Term Care to provide this service. Under normal procedures, the Long Term Care assessor determines which agency will provide service; the agency then selects, schedules and supervises the worker. Individuals may request a change of agency or worker; these requests may or may not be met at the discretion of the Long Term Care Assessor and homemaking agency.

Several new programs allow Long Term Care users increased control in their service delivery. In Vancouver, a new program operating on a trial basis called the Enhanced Consumer Participation Model allows users to select and supervise their own workers, although the homemaking agency remains the official employer. In theory, users negotiate details with their agency, but in practice, the agency often provides the person with a predetermined contract; generally users are responsible for their own back-up systems and advertising costs. Agencies may, but are not required to, pass administrative savings on to workers in the form of higher wages. In keeping with the philosophy that Long Term Care provides services to supplement assistance provided by families, family members may not be hired as attendants/homemakers. This program has not yet been approved for operation in other areas of the province. Another option called brokerage, which enables users to contract directly for their services, also operates in a few areas of the province, but is generally not available.

Information about the Program

A pamphlet briefly describing the program is available. The written Long Term Care policy manual, which includes specific details about program delivery and assessment procedures, etc., is not readily available to the public.

Size of the Program

The program currently provides over 6 million hours of homemaking service to over 50,000 clients; projected costs for 1990-91 are over \$90 million. The average number of hours provided to clients has decreased 11 percent since 1986; the average amount of assistance at the highest care level — extended care — has also decreased 12 percent in the same time period.

III. NEEDS AND GAPS

A. INPUT FROM THE LITERATURE

The review of housing and support services for persons with disabilities conducted by the G. Allan Roeher Institute, emphasizes that these services are as critical as health care in terms of their importance to the daily living of persons with disabilities and are essential to ensure equality of participation in the community (1990). Although there are variations in housing and support services in Canada, this document identifies consistent problem areas in most provinces in Canada: fragmentation of services; restrictive criteria; rigid rules; lack of portability; lack of service; administrative and attitudinal barriers; residual service provision; and the absence of standards and control. The report recommends that these support services should be universally available to individuals with disabilities across Canada, and that federal cost-sharing programs should be redesigned to ensure that all provinces in Canada are required to provide these services on a universal basis in order to receive federal funds. The report also notes that services provided by private agencies are ineligible for federal cost-shared funding.

A recent analysis of support services for persons with disabilities in Ontario (Ministry of Community and Social Services 1990) notes similar problems: confusing and inconsistent access to services, avoidable and premature institutionalization, and inadequate access to in-home and community-based services resulting in over-use and inappropriate use of high-cost services. Six principles reflect values on which reform should be based: independence and choice, community living, service accessibility, support for informal caregivers, local planning and management, and affordability.

B. INPUT FROM THE TASK TEAM

"Not only is it difficult in many cases to pull all the pieces together; sometimes fragmentation means that certain parts are missing altogether. When the missing parts are essential to a person's ability to function, the impact can be profound." **Poor Places**, 1990.

A glance at the chart summarizing support attendant/homemaker services for persons with disabilities reveals an uneven patchwork of uncoordinated services. The fragmentation presents a serious barrier to access and effective use of these services for persons with disabilities.

None of these services is ideal and many needs are unmet. The most comprehensive of these services — Day Programs under the Services for the Handicapped Branch of the Ministry of Health — provides a full array of services at no cost, but is only available to a small number of persons with disabilities: those who are assessed at the extended care level and who are also mentally handicapped. Persons who are independently mobile (personal or intermediate care levels) or persons who are not mentally handicapped are not eligible for this program. In contrast, the Ministry of Health's Long Term Care Homemaker Program offers eligibility to a much larger group of individuals, but service is restricted to the home; philosophy and program administration do not reflect the equality rights of persons with disabilities; and user fees place a severe barrier to independence for working disabled persons.

Similar discrepancies arise in other areas. For example, a disabled person with a child would not be able to obtain child-related assistance from the Long Term Care Homemaker Program. The only program that would meet this need, the Ministry of Social Services' Family Support Homemaker Program, is designed as a temporary service, which is inappropriate for these continuing needs. Again, basic needs are left unmet. Similarly, Vocational Rehabilitation Services (VRS) provides equipment, attendants, and other assistance to enable persons with disabilities to gain skills and enter the workplace. However, VRS services are only available to those persons considered employable after the training or assistance ceases: therefore, persons with disabilities who need support services at the workplace are not eligible for VRS assistance, because no provincial program currently provides necessary support services at the workplace.

But while the patchwork of support services is uneven, it does have portions which point the way to the future. Newer services, designed specifically for persons with disabilities, have many innovative features which meet the needs of participants. Of note here is the broad range of services provided by the Day Programs in the Services for the Handicapped Branch, and the innovative direct funding and application procedure in the Assistance Program for Students with Severe Disabilities. Rather than starting from scratch, the design of an effective and comprehensive support program for persons with disabilities in British Columbia could begin by including such desirable features in a new coordinated program.

C. INPUT FROM THE COMMUNITY

Overall, the submissions concurred that the current support system does not enable persons with disabilities to participate in the community. Feedback centred around a fragmented and uneven service delivery system; inadequate amounts and types of service; rigid, inconsistent and unfair assessment procedures; invasion of privacy and demeaning attitudes; lack of client control; lack of effective appeal mechanisms; lack of accurate and accessible information; and unaffordable costs, especially to employed persons and more severely disabled persons.

SPECIFIC FEEDBACK FROM THE COMMUNITY

Philosophy

- Long Term Care does not have a mandate to provide the support services required to enable persons with disabilities to live independently in the community. It should be enshrined in legislation that the Long Term Care mandate should support persons with disabilities to live independently in the community. This should include a philosophical statement and an appeal mechanism.
- Legislation governing the provision of supports should clearly outline an individual's entitlement to his or her rights. There is presently no statement of rights in the legislation, nor have any regulations been enacted.
- Many problems inherent in the programs stem from the lack of autonomy and self-determination of the individual.

Adequacy and Appropriateness of Program

- Long Term Care currently imposes an arbitrary ceiling of four hours of service per day, for a total of 120 hours per month. This amount of service is inadequate and does not support the activities of daily living of persons with disabilities.
- There is no system-wide effort to deinstitutionalize persons with physical disabilities, and there are few alternatives outside of institutions for people who cannot get by with only four hours of support per day. The result is that many people are confined to institutions because of the lack of adequate community supports.
- Many consumers express significant frustration with the restrictive policies on the role of attendants and the services they can provide; with the limited number of hours and times during which these services are available; and with who qualifies to be hired as an attendant.

- Present programs have little provision for emergency needs or temporary changes in health and support needs.
- Long Term Care Homemaker service and Family Support Homemaker service are only provided in the home. Programs denying support outside of the home are seen as denying a person any meaningful independence and participation in the community. Service should be provided in any location that meets clients' needs: in the home, at work, at school, and in the community.
- Family members or relatives cannot be hired as paid attendants; in addition, the number of allowable hours of service is reduced when a person lives with his or her family.
- Information on how Long Term Care operates is not readily available to individuals using the service, or to advocates. A recent written request to review these policy documents by the Coalition to Promote Interdependent Living was turned down by Long Term Care administrators. Restricted access to information prevents effective community input into the Long Term Care system and makes reform difficult.
- The needs of persons with disabilities who have children are not included in the mandate of Long Term Care. This effectively denies family life to adults with disabilities.
- Inadequate and inappropriate services result in increases in long term health problems and increases in costs due to hospitalization and institutionalization.
- Service provided within the Ministry of Health's Long Term Care Homemaker Program is provided under a medical model. This model is not appropriate for persons with disabilities. Persons with disabilities are not sick and will not be cured or recover. To label an individual as "sick" presupposes limitations on that individual, and presupposes the exclusion of the individual from pursuing normal life.

The medical model may be used to justify a paternalistic system in which individuals receiving "care" are not expected to retain control over their lives and are expected to succumb to a myriad of rules ordering their lives.

Administration

- The eligibility criteria for programs providing support services are not coordinated, so that many essential needs are not met by any program. The needs of a disabled parent with children, for example, cannot be met by the Ministry of Health's Long Term Care Homemaker Program; these needs can be met by the Ministry of Social Services' Family Support Homemaker Program only if the disabling condition is temporary: no ministry provides ongoing assistance to persons with permanent disabilities who have children.
- In the Long Term Care Program, support services are administered by local health units throughout the province of British Columbia and are delivered by private and non-profit health care agencies on a contractual basis. The lack of specific regulations in the Continuing Care Act has meant that there is no standardized quality of services throughout the province, and individuals receive great variation in services.
- The low wages paid to attendants and poor training of attendants result in high turnover and poor service standards. Low wages reflect the large administration fee taken by the agencies and the low value placed on attendant support work by our society.
- No effective mechanism exists to ensure quality of care. Clients have minimal input and control in the current system; workers are responsible to agencies who do not directly observe job performance.
- No independent appeal mechanisms exist to review decisions about eligibility, amount of service or type of service provided, except in the Ministry of Social Services' Family Support Homemaker Program. Independent appeal mechanisms should be established so individuals can challenge decisions of great impact on their lives.
- The cost of the homemaking service in the Long Term Care and Family Support Homemaker Programs, with minimal deductions for expenses, is unaffordable by persons with disabilities. The assessment of this fee on a daily basis in the Long Term Care program is unfair and discriminatory to persons with severe disabilities or who need daily assistance.

The cost of this service to persons with disabilities who work, especially if service is needed on a daily basis, is unaffordable and a barrier to employment. The cost to spouses is a very real barrier to family life for persons with disabilities.

- Assessments for eligibility are inconsistent, subjective, narrow in focus and not based on a person's actual need for assistance. They should be based on real needs and actual time required to meet these needs, rather than on arbitrary criteria such as mobility or the need for professional care or supervision.

IV. RECOMMENDATIONS OF THE TASK TEAM

Towards the Social Development Approach

- Support services for persons with disabilities should be seen as a basic right and an essential service. Like other essential services such as health care, this service should be seen as a shared societal responsibility and provided on a universal basis.

RECOMMENDATION NO. 42

THAT support services to enable persons with disabilities to participate in the community be provided on a free and universal basis to persons with disabilities.

- No federal cost-sharing program currently exists to finance the full range of support services to enable persons with disabilities to participate in the community.

RECOMMENDATION NO. 43

THAT the provincial government initiate provincial/federal discussions to change or develop federal cost-sharing programs which ensure the universal provision of appropriate support systems to persons with disabilities in Canada.

THAT the provincial government declare persons with disabilities "likely to be in need", so that support services can be delivered on a universal basis in accordance with the recent federal/provincial agreements regarding CAP funded programs.

Designing a Support System which Supports Community Living

- A comprehensive support program must be developed which provides assistance for all activities of daily life — work, education, recreation, family — and which is available to persons with any type of disability — physical, mental, psychiatric, learning. No gaps in service must exist, and service must be provided on an equitable basis regardless of type of disability, area of province, ministry providing service, age of client and type of family or living arrangement.

RECOMMENDATION NO. 44

THAT a complete review and reorganization of the entire system of support services be immediately undertaken in consultation with the community of disabled persons, and that the mandate to provide the full range of support services which enable persons with disabilities to participate in the community be clearly enshrined in the provincial legislation governing these programs. These support services must include assistance for participation in work, school, family life, and community activities, and must meet the principles delineated above.

- The provision of support services for persons with disabilities should not be provided under a medical model. Because persons with disabilities are not sick, there should be no greater medical presence in their lives than in the lives of persons without disabilities. The medical model creates and maintains the attitude that individuals with disabilities need "care" as opposed to "supports" or "assistance" for achieving integration in the community. Such attitudes themselves create barriers and systemic discrimination.

RECOMMENDATION NO. 45

THAT the name of any program(s) providing support services to persons with disabilities reflect the concepts of "support" or "assistance", not "care". The name must also reflect a commitment to provide service to support all the activities of community living, not just service in the home.

THAT many types of assistance that attendants are presently not allowed to perform be demedicalized and performed by attendants when the consumer directs the performance of these tasks.

Assessments

- The current assessment procedure in the Long Term Care system violates the privacy of participants and is based on criteria which do not reflect the needs of persons with disabilities.

RECOMMENDATION NO. 46

THAT the assessment procedure to determine eligibility and amount and type of service in the Long Term Care Program be substantially revised, in consultation with persons with disabilities, to ensure that assessments reflect the needs of person with disabilities, are consistent, and do not violate privacy rights. Specifically:

THAT the current 120 hour maximum in the Long Term Care system be eliminated.

THAT the current preset levels of care in the Long Term Care Homemaker Program be eliminated and replaced with an assessment procedure based on criteria relevant to a client's actual need for service. Service guidelines must be flexible and include all services necessary for persons to live productively in the community, including employment, education, family and community activities.

THAT availability of family members not be considered part of an assessment.

THAT the current Long Term Care assessment procedure be replaced with an application procedure which places the responsibility for description of service needs and documentation with the client. This application procedure must be developed in consultation with the community of persons with disabilities.

THAT the assessment/application procedures be redesigned to ensure that they do not violate the privacy rights of persons with disabilities. Only information relevant to service delivery must be collected and maintained on file: notations not relevant to a person's need for service, such as attitude, attire, smoking or drinking habits, must not form any part of an assessment/application procedure.

THAT the criteria used to determine the amount of support services for persons in the community must not be the same as the criteria used for institutional assistance.

- The needs of persons with disabilities may vary on a daily, weekly or monthly basis. There are currently no effective mechanisms to meet varying needs, nor are there provisions for temporary assistance to prevent disability.

RECOMMENDATION NO. 47

THAT support services be available for persons with temporary impairments and as a means to prevent permanent disability. Buffer hours must be included in all assessments to accommodate emergencies or temporary changes in need.

- The current financial assessment for service in the Long Term Care Program discriminates on the basis of degree of disability: persons who need daily assistance pay a fee seven times higher than those requiring weekly assistance. In addition, these financial assessment procedures are an effective barrier against employment and family life for persons with disabilities - they relegate employed persons with disabilities and partners of persons with disabilities to a life of poverty.

RECOMMENDATION NO. 48

THAT until a universal system is developed, the daily fee for service in the Long Term Care Homemaker Program be immediately eliminated or replaced with a weekly or monthly fee that does not discriminate on the basis of degree of disability.

THAT larger standard deductions for daily living expenses, employment and disability be allowed, as well as a new deduction for medical expenses. Individuals with expenses above the standard amounts must be allowed to itemize deductions.

THAT family or spousal income not be considered part of assessable income for Long Term Care or Ministry of Social Services homemaker assessments. If this income is included, exemptions must be significantly increased so that persons marrying persons with disabilities will not be relegated to the poverty level.

Consumer Control

- ▣ Support services must be provided with the understanding that the provision of service in no way diminishes the right of persons with disabilities to make their own decisions. As is the case with services for non-disabled persons, consumer choice and responsibility should be the standard of service provision.

RECOMMENDATION NO. 49

THAT support service delivery options include a full range of models, including individualized funding, brokerage models, an improved Enhanced Consumer Participation Model, and service through homemaker agencies. Clients should have the choice of which service delivery system best suits their needs, as well as choice of agency and worker.

THAT the restriction that family members cannot be hired as attendants/homemakers be removed.

- ▣ Currently, there is little or no mechanism for the input of persons with disabilities into the design and delivery of this essential service.

RECOMMENDATION NO. 50

THAT an ongoing consumer committee be established to ensure that this goal and others are effectively met.

Protecting Rights

RECOMMENDATION NO. 51

THAT regulations be enacted for all programs providing support services, in consultation with the community of disabled persons, to protect the rights of participants and ensure that service standards are established and met.

THAT an independent appeal mechanism be established to review decisions on all aspects of service including eligibility, amount, and type of service for all support service delivery systems.

THAT consumers be guaranteed the right to access their files.

Service Delivery

- Quality of service is impeded by low wages, high turnover, uneven training, ineffective service standards, and poor accountability procedures.

RECOMMENDATION NO. 52

THAT wages to homemakers/attendants be substantially increased to reflect the variety of skills required and the value of the work. Training and implementation of service standards should be done in consultation with clients, so that training is relevant and effective. Service delivery systems must be accountable to the persons receiving the service.

- The provision of service through non-profit agencies has advantages because these agencies generally return a higher percentage of their billing rates to their workers, and because the federal government will only cost-share homemaking service provided through non-profit rather than profit making agencies.

RECOMMENDATION NO. 53

THAT priority for service delivery be given to agencies that best meet the criteria of federal/provincial cost-sharing programs and to agencies which provide higher wages to workers.

FOUR SUPPORT PROGRAMS IN BC: A COMPARISON

Program Name	Long Term Care/Homemaker Services	Family Support Homemakers	Day Programming	Assistance Program for Students with Severe Disabilities
Ministry	Health.	Social Services.	Health.	Advanced Education, Training and Technology.
Division	Continuing Care.	Family and Child Services (policy).	Family Health Division, Services to the Handicapped Branch.	Administrative & Support Services, Student Services Branch.
Philosophy	Promote personal independence; personal/family responsibility & involvement in planning/providing care, normal life style. Underlying principle: Individuals responsible & wishing to care for selves/families - program is therefore supportive; provides care only when personal/family resources not able to. Recognizes right to remain at home as long as feasible.	Services to individuals with mental handicaps: access to all services available to non-handicapped people; services designed to maintain/strengthen independence; services support integration; dignity of individual respected - encouraged to act on own behalf; support unique strengths of individuals; support families; treat with respect, fairness, courtesy.	1) Individuals with disabilities have right to determine own goals, access community services, privacy, appropriate health care, all other rights non-disabled people enjoy 2) importance of family 3) optimal development of individuals 4) respect dignity of individuals with disabilities/help prepare for risks 5) facilitate integration 6) programs cost effective.	Very brief description of program/philosophy, new program: enable persons with severe disabilities to access post-secondary education.
Program designed for?	Seniors; designed to assist seniors to remain in their homes rather than be institutionalized.	Children and their families.	Adults with multiple disabilities, coming out of institutions, to support full participation in community living.	Students with severe disabilities.
Purpose	Provide comprehensive/coordinated continuum of services appropriate to continuing health care needs; maximize number clients receiving care at home; primary responsibility - family.	Provide temporary support & relief to individuals & families to maintain or restore independent functioning in community; not intended to relieve persons/families of functions they can/should assume themselves.	Provide whole range of assistance to enable persons with severe multiple disabilities to participate fully in all activities of community; provide services to support deinstitutionalization in a way that empowers/supports individuals.	Provide direct grants to individuals with severe disabilities for essential services & equipment to facilitate access to post-secondary education.
History of Program	Started in 1978 to help seniors stay in homes - authorized by Order in Council until 1990; program broadened to include persons with disabilities - no specific program/assessing changes made to accommodate disabled persons' needs, except enhanced participation model (1990).	Designed to provide temporary assistance to children & families; expanded to include assistance to adults with mental handicaps, persons temporarily ill/disabled, respite care. Broad mandates cover many situations; mandate not changed to cover long term needs, but in practice recognized that temporary assistance not sufficient for many needs, including adults with mental handicaps.	New program: four years old. Branch started 1986 to support the deinstitutionalization of multiply-handicapped persons from Tranquille, Glendale & Woodlands. Broadened to include multiply handicapped persons coming out of other institutions, then to include children turning 19 in group homes, now includes all multiply-handicapped persons in the community or going to community.	New program, three years old. Started as forgivable loans program for full time students with severe disabilities who needed assistance to participate in college or university education. Now is grant program and includes assistance for part-time students.

FOUR SUPPORT PROGRAMS IN BC: A COMPARISON

Program Name	Long Term Care/Homemaker Services	Family Support Homemakers	Day Programming	Assistance Program for Students with Severe Disabilities
Eligibility	Adults (19 years or more) with long-term or chronic illness or condition - defined as no recovery in less than 3 months; must be BC resident minimum 12 months.	Families/individuals who meet broad criteria: support normal family routine if parent(s) temp unable; prevent family breakdown; improve childcare household management skills; support mentally handicapped adults in community living (if no LTC); temporary assistance to individuals in crisis. Yes, if not served by LTC. Yes, if not served by LTC. Yes, if meet criteria.	Multiply-handicapped individuals - must be mentally handicapped and physically disabled at the extended care level (not able to transfer independently).	Students with severe disabilities, registered at a post-secondary institution, who would not be able to access post-secondary education without this assistance. Students must demonstrate that this need cannot be met by other resources.
Type of Disability physical psychiatric mental handicap learning dis.	Yes. Yes. Yes, if at extended care level. Only if meet other criteria.		Only extended care + ment hand. Only if meet other criteria. Yes, must be extended care also. Yes, if meet other criteria.	Yes. Yes. Yes. Yes.
Type of assistance	Homemaking/attendant duties in home. Provincial & local guidelines specifically outline which tasks workers allowed to perform.	Homemaking/child/family support in home; assist mentally handicapped adults in community - see above. No specific guidelines for allowed tasks; line workers have discretion.	Any assistance to enable multiply disabled persons to participate fully in the community.	Assistance (attendant care, interpreters, technical aids, equipment etc) to enable students with severe disabilities to access post-secondary education.
home work school recreation parenting/childm	Yes, only. No. No. No. No.	Yes, designed to be in home. No (not explicitly prohibited). No (not explicitly prohibited). No (not explicitly prohibited). Yes.	Yes. Yes. Yes. Yes. Yes.	No. No. Yes. No. No.
Length of assistance	Long term.	Temporary, up to 3 months/monthly review; may be extended in 3 month intervals with District Supervisor's approval; if more than 12 months, Area Manager must approve.	Long term.	One calendar year.
Maximum assistance	120 hours/month; hours over maximum must be authorized by Unit Supervisor/Reg. Director Home Support Services; must notify Victoria - happens infrequently, usually temporary (often palliative).	125 hours per month; hours over maximum must be authorized by District Supervisor - no information available on how often this happens.	No set maximum; range usually 3-6 hours/day.	\$10,000 maximum grant per student per calendar; students use grant to purchase pre-approved assistance required.
Average assistance	12.7 hours/month/1990-91 (pers. care 6.6; interned. 11-33; extended care: 51). Average hours decreased 11% from 1984-85 to 1990-91.	Approx. 29 hours/month/1988-89 - (exact #'s not avail; average hours Long Term Care 88-89: 12.3/month). Figures not available for 1990-91.	Approx. 100 hours/month per person (includes some assistance not 1:1); exact figures not available.	Average amount of funding given to each student - \$5-6,000.

FOUR SUPPORT PROGRAMS IN BC: A COMPARISON

Program Name	Long Term Care/Homemaker Services	Family Support Homemakers	Day Programming	Assistance Program for Students with Severe Disabilities
Who assesses	Long Term Care Assessors in Health Departments. In many instances, persons with psychiatric disabilities are assessed by Mental Health Services staff who often operate in different offices.	Line workers at any of three Ministry offices: Income Assistance, Family & Child Services, Services for People with Mental Handicaps (sometimes these offices are separate, sometimes combined).	Service Coordinators and Regional Coordinators.	Three person committee reviews applications: Coordinator of Vocational Rehabilitation Services; Coordinator of Special Programs, Student Services Branch; and Adult Special Education Coordinator.
Assessment Application procedure	Client assigned to one of three categories of care: - personal care (up to 48 hrs/month) - no professional or nursing care required; - intermediate care (up to 98 hrs/mth) - professional or nursing care required; - extended care (up to 120 hrs/mth) - not able to transfer independently or walk more than 10-15 feet. Assessors have no discretion in assigning level of care; policy specifically states assessment must be based on criteria, not on client's perceived need for service. Amount of care within categories determined by client's condition & availability of support from other sources. Extensive written guidelines with assessing criteria/characteristics of each level of care; criteria subject to interpretation, assessor has discretion. Same criteria used to assess level of care for institutions & persons in community. Many criteria refer to psychological/social level of functioning.	No specific assessing guidelines; assessment based on social need, availability of assistance from family members, and functional ability where appropriate. Mandate for service very broad; much discretion/flexibility in determining hours. Clients who are already in the community require Long Term Care assessments confirming support needs at the Extended Care Level and that the client has a mental handicap.	No specific guidelines; amount and type of care negotiated with client, family, advocates etc. Students must first explore other avenues of support including Vocational Rehabilitation Services. Student submits application, with letters of support and documentation of need plus support plan.	No specific guidelines. Student designs own service plan including who, how, costs etc - Special Educational Coordinators or Financial Aid Officers may assist in completing application or designing service plan. Applications available from Special Education Coordinators or Financial Aid Office at post-secondary institution where student is registered.
Family assistance considered in assessment	Yes.	Yes.	No.	Yes.

FOUR SUPPORT PROGRAMS IN B.C. A COMPARISON

Program Name	Long Term Care/Homemaker Services	Family Support Homemakers	Day Programming	Assistance Program for Students with Severe Disabilities
Financial assessment - cost of service to client	Income tested, assets not considered, user fees paid on sliding scale; assessable income is determined by subtracting following deductions from net income: • \$ 618/single person (\$937/2 persons, \$1074/3 pers) • \$ 125 disabled/senior • \$ 100 working adult Deductions for medical expenses, equipment not allowed; expenses may not be itemized. After allowed deductions, remaining net income is divided by 60 to determine daily fee for service. For persons who need help every day, this is half of net income after allowed deductions. If fee poses hardship, client can be referred to Min Social Services for 6 month fee exemption/temporary hardship assessment procedure - liquid assets must be used first, no other possible sources of help; procedure rarely used.	Income tested, assets not considered, user fees paid on sliding scale; assessable income is determined by subtracting following deductions from net income: • \$600 single person (\$997 2/pers, \$1133 3/pers) • \$125 disabled/senior • \$100 working adult or post-secondary student Deductions for medical expenses, equipment not allowed; expenses may not be itemized. After allowed deductions, remaining net income is divided by 2 to determine monthly service fee (Director may assess daily user fees - no details). Fees paid for other supports from the Ministry (eg Day Care) may be subtracted from Homemaker user fee. If fee poses a hardship, a needs test may be applied - this is infrequently done/no specific procedure is outlined.	Clients are usually already income tested. No fee for service.	Needs test. Student must demonstrate in application that she/he does not have resources to purchase/receive necessary services (or equipment) from other sources.
Spousal/family income included?	Spousal income included in assessment (deduction \$319 higher for couple). After additional \$319 deduction, spousal net income added to client's income & divided by 60 to determine per diem fee. If client designated disabled by Min Social Services, spousal income exempt until spouse retires (her/his income then not earned income; must include in assessment). To obtain handicapped designation, client must apply to MSS; same procedure to receive HPIA (see Chapter on income support).	Spousal income (& income from dependants) included in assessment (deduction \$397 higher for couple). After this additional \$397 deduction, spousal net income added to client's income & divided by 2 to determine monthly fee. If client designated disabled, spousal income exempt until spouse retires (her/his income is then not earned income/must be included in assessment). To obtain handicapped designation, client must apply to MSS/same procedures to receive HPIA (see Chapter on income support).	Spousal/family income not included.	Spousal income included; parent's income only usually considered if student under 19 and living with parent. There are no set rules - each case is assessed individually for exceptional circumstances. Generally use same criteria as used for loans to post-secondary students (B.C. Student Assistance Program).

FOUR SUPPORT PROGRAMS IN BC: A COMPARISON

Program Name	Long Term Care/Homemaker Services	Family Support Homemakers	Day Programming	Assistance Program for Students with Severe Disabilities
Choice of Agency	No. Assessor selects agency/may follow client's requests or not. Client may request change of agency (unwritten procedure: client tries to resolve problem with agency first; then Long Term Care will consider request for change).	No. Line worker selects agency; line worker has discretion to follow client's requests or not.	Choice of agency is determined with client/family/advocates whenever possible.	Yes. Student/client has complete control over which agency provides service or student/client may choose to independently hire assistant(s) as long as plan is approved in application & allocation of funds is appropriately reported.
Choice of worker, client control	No. In regular program; yes, in enhanced consumer participation model/trial basis, Vanc; clients need LTC assessor's approval to partic. In enhanced partic. model, client advertises for potential workers (at client's expense), & chooses worker, subject to agency approval. Agency is official employer, but rarely interferes. In theory, clients negotiate individualized contracts with agency; in practice, agencies often use standard contracts. Agencies not required to pass savings to workers; client coordinates back-up system.	No.	Client is given as much control/choice as possible; if service is provided on a one-to-one basis, client/family/advocates are usually involved in choice.	Depends on service provision model client designs/chooses. If client chooses to hire assistant her/himself, client has complete control. If client hires through agency, choice would depend on individual arrangement made.
Who supervises worker?	Agency, except for participants in enhanced consumer participation model.	Agency.	If agency contracted to provide service, agency supervises; if branch directly contracts, branch staff supervise; client participates to degree feasible.	Depends on service provision model client designs/chooses. If client chooses to hire assistant her/himself, client has complete control. If client hires through agency, supervision depends on individual arrangement.
Can family member be employed?	No.	No.	No.	Yes, each application and request is reviewed individually.
Money given directly to client?	No, but several brokerage models in the interior of BC through North Okan Handicapped Association & Independent Living Centres - money given to Independent Living Centre, then funneled to client.	No.	No.	Yes. Money given directly to client to purchase approved assistance. Client submits quarterly disbursement reports & receives money in quarterly instalments.

FOUR SUPPORT PROGRAMS IN BC: A COMPARISON

Program Name	Long Term Care/Homemaker Services	Family Support Homemakers	Day Programming	Assistance Program for Students with Severe Disabilities
Legal Authority	Continuing Care Act (1990); previously order in council. Act has little detail; Minister of Health given broad authority to determine eligibility, payment guidelines etc. No rights or philosophy in legislation.	GAIN Act, regulations Section 27.	None.	General Order in Council #1038.
Regulations	None.	Regulations specify mandates for service, appeal procedures, etc.	None.	None.
Written Policy	Yes; written in 1983.	Yes.	No - new program, has philosophy statement (below).	Very brief. New program.
Appeal procedures	Internal appeal to Unit Supervisor.	Independent appeal to tribunal <u>only</u> if specific case is made that an expense would be incurred if service was not provided (this has been successfully argued in the past). Otherwise, internal appeal.	No specific appeal mechanism.	Appeal to three person committee who made original decision; on request, application may go before the Appeals Committee for the British Columbia Student Financial Aid Program.
Information available to public?	No; pamphlet available, few details. Policy manual not readily available to public.	Pamphlet available on services to persons with mental handicaps; no other pamphlets available. Policy manual available on request.	No specific mechanism - word of mouth.	No - Information was sent to Vocational Rehabilitation Services, Financial Aid Workers and Special Needs Counsellors in colleges and universities.

FOUR SUPPORT PROGRAMS IN BC: A COMPARISON

Program Name	Long Term Care/Homemaker Services	Family Support Homemakers	Day Programming	Assistance Program for Students with Severe Disabilities
Federal cost-shared?	Yes - 50% federal funds under CAP welfare. In order to receive federal cost-shared dollars, income tests must be given - persons receiving free service must be in financial need; income tests (& fee for service) can be waived if group of persons is deemed likely to be in need (new federal/provincial guidelines say disabled persons can be considered likely to be in need). Assistance with education, recreation or cultural activities specifically prohibited. Only service provided by non-profit agencies is federally cost-shared: 25% of LTC homemaker costs not cost-shared from 1984-90 because service provided by profit-making agencies.	Yes - 50% federal funds under CAP welfare. In order to receive federal cost-shared dollars, income tests must be given - persons receiving free service must be in financial need; income tests (& fee for service) can be waived if group of persons is deemed likely to be in need (new federal/provincial guidelines say disabled persons can be considered likely to be in need). Assistance with education, recreation or cultural activities specifically prohibited. Only service provided by non-profit agencies is federally cost-shared: 29% of Family Support Homemaker costs not cost-shared from 1984-90 because service provided by profit-making agencies.	No. Only provincial funding.	No. Only provincial funding.
Budget history	Over \$90 million, 6 million service hours, approx 40,000 clients/month - 1990-91. 93.5% of clients are seniors - 3680 under 50, 1990-91. Budget increased 94% since 1984-85, but average hours/client decreased 11%, mainly due to increases in service costs.	Approx \$6 million - 1990-91 (no info available on # service hours or clients 90-91). In 1989-90, \$5.1 million for 1896 clients/month. Budget increased 66% since 1984-85 (info not available on number of service hours or clients).	Exact figures not available - approx \$15-20,000 spent per client on day programs per year. Budget increased substantially as more individuals deinstitutionalized; planning process includes allocations for current clients, persons coming out of institutions & persons turning 19.	\$100,000 1990-91. In 1989-90, 15 students received assistance.

CHAPTER SEVEN
HARMONIZATION OF SERVICES

- I. INTRODUCTION
- II. HARMONIZATION OF PROGRAMS IN B.C.
- III. INFORMATION FROM THE LITERATURE
AND FROM THE SUBMISSIONS
- IV. RECOMMENDATIONS OF THE TASK TEAM

I. INTRODUCTION

The previous chapters reviewed and analyzed particular programs for persons with disabilities, but reserved discussion of the extent to which these programs fit together in a mutually reinforcing fashion for the final chapter. It is entirely appropriate that this crucial issue of the harmonization of services be addressed in the final chapter.

The Task Team chose the term "harmonization" of services rather than "coordination", "cooperation", "collaboration" or "integration" simply because these traditional terms have been used for such a long period of time that different shades of meaning are attached to them. The Task Team decided it would be preferable to coin a new phrase and define it in a precise manner, and by so doing, eliminate the customary semantic disagreements. Harmonization refers to the way in which services are arranged and made available to consumers. A high degree of harmonization occurs when a policy (and "policy" refers here to an overall statement of purpose or mission expressed in the form of legislation or some other formal declaration) has been established and is used to guide the subsequent development of programs.

A discordant pattern occurs when programs are developed in the absence of a guiding policy. Programs are then initiated in a piecemeal fashion without reference to each other, with the consequence that there is no overall symmetry or logic to the pattern of services. A study of housing programs in Ontario concluded that they were "programs in search of a policy" (Dennis and Fish, 1972). The review of programs conducted for the Task Team by Marvin Shaffer and Associates made a similar observation with respect to services for persons with disabilities in B.C.:

The Governments of British Columbia and Canada have no systematic approach to identifying or addressing the problems of people with disabilities. A wide range of public and private initiatives exist with varying definitions of disability criteria and programs and services. There is no apparent unifying principle or application of principles. Persons with disabilities are largely left to their own wits to locate, identify and apply for programs and services which they can use to address their disability needs. Their search may be aided by persons involved in the delivery of specific programs or services.

Based on the submissions received and a review of the literature, the Task Team is in complete agreement with the above conclusion: governments in British Columbia have never developed a statement of policy to guide the development of services for persons with disabilities.

II. THE HARMONIZATION OF PROGRAMS IN B.C.

The catalogue prepared by Marvin Shafer and Associates contains an inventory of programs provided by ministries of the provincial government and Crown Corporations for persons with disabilities. The following table, based on the catalogue, illustrates the range of programs currently available:

AREA OF SERVICE	NUMBER OF PROGRAMS	MINISTRIES
Income	3	ICBC, Ministry of Social Services; Worker's Compensation (plus the Canada Pension Plan)
Housing	11	Ministry of Health; Ministry of Municipal Affairs, Recreation & Housing
Transportation	6	B.C. Ferries; BC Transit; ICBC; Ministry of Finance (plus Revenue Canada)
Medical Services, Technical Aids, Equipment and Supplies	13	Ministry of Advanced Education, Training & Technology; Ministry of Social Services
Employment, Training and Education	13	Ministry of Advanced Education, Training & Technology; Ministry of Education and Ministry of Social Services
TOTAL:	46	Six Ministries, Four Crown Corporations

It is not the intent here to provide a detailed analysis of the similarities and the gaps among the above programs. Nevertheless, some appreciation of the lack of harmonization can be found from a simple listing of the housing programs offered by the Ministries of Social Services and Health.

1. Community Residences Program for adults with mental handicaps (M.S.S.).
2. Semi-independent living programs for adults with mental handicaps (M.S.S.).
3. Short Term/Respite Care for persons with disabilities living at home (M.S.S.).
4. Intensive Adult Care Services (short term) for persons with mental handicaps and severe behaviour problems (M.S.S.).
5. Adult Residential Services for adults with multiple handicaps (Health).
6. Long Term Care and Transitional Homes for persons with head injuries (Health).
7. Licensed Residential Homes for individuals with serious mental illness (Health).
8. Family Care Homes for individuals with mental health problems who do not require intensive care (Health).
9. Rent Subsidized Facilities for individuals with mental health problems capable of semi-independent living (Health).
10. Residential Care Facilities — continuing care for individuals with physical or mental health problems (Health).
11. Rent Subsidies for low income seniors, families and persons with disabilities (B.C. Housing Corporation).

It should not be inferred from the above list that the programs presently in place meet all the housing needs for persons with disabilities. Indeed many are in urgent need of expansion. The enumeration is provided to establish the essential argument of this chapter — that services have been developed in response to particular needs identified by particular groups at particular times and in the absence of an overall statement of philosophy and policy.

Further evidence of the discordant pattern of services is contained in the previous chapter. Support services for persons with disabilities are provided through eight different programs from three ministries. Each of these eight programs was developed independently of the others. Many were designed to meet the needs of children and the elderly and were later expanded to include persons with disabilities.

A number of consequences of this muddling-through approach in the development of services for persons with disabilities can be identified. First, there is no fixed point of responsibility at the direct service or the policy level when services are scattered across a number of ministries. In the absence of fixed points of responsibility, decisions regarding the most appropriate service for a particular individual can be shuttled back and forth between direct service workers and between ministries. In turn, and particularly when coupled with a shortage of resources, consumers who do not neatly fit a set of eligibility criteria, or who exhibit some impatience when applying for services, can be shunted on a seemingly endless referral chain between ministries and other organizations.

A second consequence is that it is difficult, if not impossible, to monitor and evaluate a set of fragmented programs. Which ministry and department is responsible for ensuring that services are effective and for accounting to funders and to consumers, when functions are split among many organizational units?

A third consequence is that an array of programs tends to provide a false sense of security for consumers and policy makers. The existence of a number of programs can obscure the reality of gaps among the various programs. Thus the listing of housing programs contained above might at first glance indicate that all housing needs for adults with disabilities have been met. However, as noted in the Housing chapter, such is far from the case in B.C.

The final consequence noted here is that of confusion. Consumers encounter difficulties in securing information about programs, about the differences in eligibility criteria, about the differences in benefits and coverage and about the availability of some programs in their community. Indeed, not only consumers, but staff members of ministries and of agencies serving persons with disabilities, are often confused about the details of programs, and hence find it difficult to provide accurate information to consumers.

All of the above consequences of the patchwork-quilt approach to service provision are graphically portrayed in the following account of a mother trying to locate appropriate services for her son. The account concerns services for children rather than adults with disabilities, but the journey through the labyrinth of services is no different for adults than it is for children. Indeed, one of the advantages in children's services is that parents are sturdy and committed advocates, whereas adults are frequently on their own.

"We [parents who have children with a mental handicap] discovered that we had all been sent down different tunnels just to be sent back again. We would call somebody who was supposed to be the support authority in the community and we'd say: "This is our need." And they'd say: "You're in the wrong place but if you go over to that person and go down that tunnel or go to those services you'll be fine." So you go to that service and you go down another tunnel and there is nothing at the end again. They'd send you to another desk or another office over and over again until finally you had exhausted all the desks or all the tunnels and before you knew it you were standing there by yourself with your son or daughter. And there was nobody that you could turn to. I can remember the day that I went to the person at the Ministry of Human Resources in B.C. who was supposed to be the ultimate authority in giving us something in terms of our son.... only to be told there was nothing she could do. So I went home. There was nowhere else to go ... so I just went home. And we all have that same story." (Poor Places, 1990).

III. INFORMATION FROM THE LITERATURE AND FROM THE SUBMISSIONS

INFORMATION FROM THE LITERATURE

There is a voluminous literature on the coordination of health and social services in Canada. The major studies conducted in the last few decades at the national level include **One Million Children** (The Celdic Report 1972); **Community Multi Service Centres** (Hepworth 1976); **Planning For Social Services** (Wharf and Carter 1977); **The Commission of Inquiry on Health and Social Welfare in Quebec** (1976); **The Community Health Centre in Canada** (1972); **Community Based Health and Social Services** (Canadian Council on Social Development, 1985); and **The Role of Local Government in the Provision of Health and Social Services** (Manga and Muckle, 1987). To list the provincial studies would require more space than is available here. Three points of interest to this discussion can be gleaned from the above and related studies.

The first is that concern for harmonization occurs when, in the absence of an overall policy, an array of services have been developed. Concerns are unlikely to be expressed until the range of programs is sufficiently extensive to cause confusion among consumers and service providers. In other words, the lack of harmonization is not a problem when there are only a few, inadequately developed programs. Previous studies have focused on social and out-patient health services for children and families, while recent provincial studies have dealt with services for the elderly. It seems apparent that having developed an extensive but essentially ramshackle pattern of services for persons with disabilities, it is now necessary to tackle the issue of harmonization.

Secondly, many of the above reports called for the integration of health and social services. With the notable exception of the **Report of the Commission of Inquiry on Health and Social Welfare** (The Castonguay/Nepveu Report 1976), which led to a fundamental reorganization of health and social services in Quebec, the recommendations of these reports have been largely ignored. Reasons for the lack of attention to implementation are not difficult to find. Large-scale reorganizations typically encounter resistance and in particular recommendations advocating the amalgamation of health and social services provoke resistance from the medical profession.

A third and important point for this report is that studies of harmonization have usually concluded with the recommendation that services should be integrated, decentralized and placed under the jurisdiction of some form of community or regional control. Such recommendations do not fare well with provincial politicians and bureaucrats, who are legitimately concerned about the need for standards and for the availability and accessibility of services on a province-wide basis.

The major inquiries and studies of services for persons with disabilities which have been conducted in recent years have focused on the substantive issues of poverty and housing (The G. Allan Roeher Institute, 1987 and 1990) and unemployment (The Standing Committee on the Status of Disabled Persons, House of Commons, 1990) and not on harmonization. However, despite the absence of national studies on the issue of harmonization, there is substantial evidence from the reports commissioned by the Task Team, and from the submissions received, that this is a serious problem for persons with disabilities in British Columbia.

INFORMATION FROM THE SUBMISSIONS

Forty-nine submissions to the Task Team commented on the lack of harmonization in programs. While income security, the adequacy of GAIN and its administrative arrangements were dealt with in some detail in Chapter Two, it is worth emphasizing that nine submissions referred to the GAIN program as an issue in the harmonization of services. These submissions noted that regulations governing access to benefits and services are complex and change frequently, as do staff members. The consequence for consumers is that unless one is fortunate enough to have an experienced and knowledgeable staff member who is prepared to act as an advocate for consumers, the full range of benefits may well not be made available.

Many submissions noted that the lack of harmonization was a general and pervasive problem for persons with disabilities and that the absence of a central information service makes access to services difficult, even in urban areas. As in all matters affecting persons with disabilities, rural living compounds the problems. Many submissions recommended that comprehensive service centres be established on a regional basis in order to overcome the problem.

Other submissions noted the lack of harmonization with respect to: the transition from institution to community (3), the transition from adolescence to adulthood (2), equipment (4) and the need for a comprehensive case management system (4).

The conclusion of the Task Team is that harmonization is not a question solely of structural reorganization. Services have been reorganized numerous times without producing substantial changes in the quality of service provided to people with disabilities. Certainly, the answer does not lie in centralization, nor necessarily in the creation of a single ministry. One large bureaucracy could simply mean less flexibility and fewer innovations.

Clearly, what is needed in British Columbia is an overall policy based on a philosophy of service which supports and respects the rights of persons with disabilities. Such a policy must be anchored in the social development approach discussed in Chapter One, and must involve persons with disabilities in designing the programs they require for all daily activities — work, education, recreation and family life. These programs must be adequate, accessible, and designed in such a way that they are mutually reinforcing and harmonious.

The Task Team is of the view that the first priority must be given to developing this philosophy of service and statement of policy.

IV. RECOMMENDATIONS OF THE TASK TEAM

STATEMENT OF PRINCIPLES AND PROGRAM PHILOSOPHY

■ RECOMMENDATION No. 54

THAT the provincial government, in conjunction with the Premier's Advisory Council, develop and establish in legislation an overall statement of policy to guide the reform and development of programs affecting people with disabilities. This statement must ensure that services:

- 1) are individualized;**
- 2) are universally available regardless of type of disability or ability to pay;**
- 3) are respectful of consumer choice and determination;**
- 4) facilitate and support the full and equal participation of people with disabilities in community life, including education, employment, recreation, culture and family life;**
- 5) have a clear rationale and are organized in a manner that is accessible to consumers and ensures effective service delivery;**
- 6) recognize the equality rights of people with disabilities, including the right to self-determination, the right to privacy, and all other rights enjoyed by other citizens.**

- All government operated and funded programs for people with disabilities would be required to function in a manner consistent with this policy statement.

RECOMMENDATION NO. 55

THAT the Cabinet Committee on Social Policy be given responsibility for establishing a review process to ensure that all legislation, policies and programs are consistent with the policy statement by December, 1994.

ACCESS TO INFORMATION

- A frequently raised concern in Task Team hearings was the difficulty people with disabilities had getting access to information on the programs and services potentially available to them. Information was difficult to acquire, often incomplete, and hard to understand or interpret. Many people expressed a desire for a single point of access to information about services.

RECOMMENDATION NO. 56

THAT the Provincial Government implement a policy on information for people with disabilities which is based on the following principles:

- Information is clearly stated in plain language.
- Information is provided in a format accessible to the individual.
- Information must be complete and indicate all available options.
- Government personnel are obligated to provide consumers with full information, including information on program policies.
- Persons with disabilities have access to their own files.

RECOMMENDATION NO. 57

THAT the provincial government develop a single point of access for information on the comprehensive array of services available to people with disabilities.

DISPUTE RESOLUTION

- One element of the GAIN program that has been identified as very successful is the appeal process. Through this process, many individuals have achieved redress from unfair administrative decisions. Unfortunately, other programs do not have a similar process. In order for a system to operate in a just and equitable manner, individuals seeking services and supports must have the power to dispute decisions which deny them these services and supports.

RECOMMENDATION NO. 58

THAT the provincial government implement a universal dispute resolution process which would apply to all programs for people with disabilities.

APPENDICES

- | | |
|-------------------|--|
| APPENDIX A | Mandate of Premier's Advisory Council
for Persons with Disabilities |
| APPENDIX B | Guidelines for Community Input |
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| APPENDIX E | Ministry of Health
Philosophy Statement |
| APPENDIX F | Summaries of Research Papers |

APPENDIX A

**MANDATE OF PREMIER'S ADVISORY COUNCIL
FOR PERSONS WITH DISABILITIES**

Certified correct as passed Third Reading on the 22nd day of June, 1988
Ian D. Izard, Law Clerk.

PROVINCIAL SECRETARY AND MINISTER
OF GOVERNMENT SERVICES

BILL 42 - 1988

**PREMIER'S ADVISORY COUNCIL FOR
PERSONS WITH DISABILITIES ACT**

Mandate of council

3. The council may

- (a) review, advise on and make recommendations with respect to government programs and policies with a view to improving the quality of life of persons with disabilities,
- (b) bring before the Premier, the government and the public, matters of interest and concern to persons with disabilities, and
- (c) without limiting the generality of paragraphs (a) and (b), promote
 - (i) the achievement of equitable access to services for persons with disabilities,
 - (ii) greater understanding of the services required by, and available to persons with disabilities,
 - (iii) public education and awareness of the capabilities of persons with disabilities,
 - (iv) prevention of disabilities,
 - (v) education and training for persons with disabilities,
 - (vi) employment for persons with disabilities, and
 - (vii) the independence and self responsibility of persons with disabilities.

APPENDIX B
GUIDELINES FOR COMMUNITY INPUT



PREMIER'S ADVISORY COUNCIL FOR PERSONS WITH DISABILITIES

PUBLIC HEARINGS FOR COMMUNITY INPUT

The Community Services Project of the Premier's Advisory Council will review current government policies and programs which have an impact on adults with disabilities living in the community, with a view to identifying factors which promote individual dignity and autonomy.

Public hearings will be held to receive oral presentations from the community. Where possible, we would appreciate written briefs to accompany oral presentations. Should you have any special needs for participating in the hearings, please advise us at 660-1155.

Public hearings will be held as follows:

JANUARY 22, 1991	KELOWNA
JANUARY 24, 1991	CASTLEGAR
JANUARY 29 and JANUARY 30, 1991	VICTORIA
JANUARY 31 and FEBRUARY 1, 1991 (One and a half days)	VANCOUVER
FEBRUARY 5, 1991	PRINCE GEORGE

We also welcome submissions in written, audio, or other formats for your convenience.
ALL SUBMISSIONS SHOULD BE RECEIVED BY FEBRUARY 28, 1991.

For those interested in making a submission to the Community Services Project, contact the Premier's Advisory Council offices at:

660-1155
TDD 660-4594
1-800-663-1107

We will provide guidelines for making submissions.

PREMIER'S ADVISORY COUNCIL FOR PERSONS WITH DISABILITIES

COMMUNITY SERVICES PROJECT

GUIDELINES FOR COMMUNITY INPUT

SUBMISSION DEADLINE: FEBRUARY 28, 1991

You may complete this form in part or in whole or you may use the headings to guide you in making your submission. Our request for input refers to people with **ALL** disabilities.

1. PROGRAMS/POLICIES PERTAINING TO INCOME ASSISTANCE AND PERSONS WITH DISABILITIES

Please comment on the following:

- a. Adequacy of GAIN assistance, allowances for transportation and training, and comforts allowance.
- b. Eligibility Criteria: appropriateness of eligibility criteria and regulations governing income from other sources.
- c. How effectively the program is administered.
- d. Other issues and suggestions for program/policy change.

2. POLICIES PERTAINING TO IN-HOME SERVICES

These services may be provided by the Ministries of Health and Social Services and Housing. Please indicate which ministry you are commenting on.

Please comment on the following:

- a. HOME SUPPORT SERVICES
 - (i) Accessibility
 - (ii) Adequacy (including costs to the individual).
 - (iii) Effectiveness/appropriateness of delivery of service.
 - (iv) Other issues and suggestions for program/policy change.

b. HOME CARE SERVICES

- (i) Accessibility
- (ii) Adequacy (including costs to the individual).
- (iii) Effectiveness/appropriateness of delivery of service.
- (iv) Other issues and suggestions for program/policy change.

c. HOMEMAKER SERVICES

- (i) Accessibility
- (ii) Adequacy (including costs to the individual).
- (iii) Effectiveness/appropriateness of delivery of service.
- (iv) Other issues and suggestions for program/policy change.

d. ATTENDANT SUPPORT SERVICES

- (i) Accessibility
- (ii) Adequacy (including costs to the individual).
- (iii) Effectiveness/appropriateness of delivery of service.
- (iv) Other issues and suggestions for program/policy change.

e. OTHER SUPPORTS FOR INDEPENDENT COMMUNITY BASED LIVING
(including those required for the transition from institution to community)

- (i) Accessibility
- (ii) Adequacy (including costs to the individual).
- (iii) Effectiveness/appropriateness of delivery of service.
- (iv) Other issues and suggestions for program/policy change.

3. POLICIES PERTAINING TO MEDICAL COSTS, EQUIPMENT AND TECHNICAL AIDS

These services may be provided by the Ministries of Health, and Social Services and Housing. Please indicate which ministry you are commenting on.

Please comment on the following:

a. MEDICAL COSTS

- (i) Accessibility of information about program/policy.
- (ii) Adequacy (including cost to the individual).
- (iii) Effectiveness/appropriateness of delivery of services.
- (iv) Other issues and suggestions for program/policy change.

b. EQUIPMENT AND TECHNICAL AIDS

- (i) Accessibility of information about program/policy.
- (ii) Adequacy (including cost to the individual).
- (iii) Effectiveness/appropriateness of delivery of services.
- (iv) Other issues and suggestions for program/policy change.

4a. OTHER SUPPORT SERVICES (COUNSELLING, OCCUPATIONAL/PHYSIOTHERAPY, LIFE SKILLS TRAINING)

These services may be provided by the Ministry of Advanced Education, Training and Technology, the Ministry of Health and the Ministry of Social Services and Housing. Please indicate which services and ministry you are commenting on. Please provide your comments and suggestions on:

- (i) Adequacy and accessibility of existing programs/services.
- (ii) How effectively they are delivered.
- (iii) If and how they should be changed.

4b. COMMENT ON OTHER ISSUES AND SUGGESTIONS FOR NEW PROGRAMS WHICH MAY BE NEEDED

5. **SERVICE DELIVERY**

Identify significant issues on service delivery which:

- (i) Affect access to information.
- (ii) Pertain to interministerial coordination of services (i.e. gaps in services, overlapping services, inconsistencies).
- (iii) Pertain to changes in status from child to adult services.
- (iv) Pertain to accountability, monitoring of services and appeal mechanisms.
- (v) How effectively they are delivered.

6. **PLEASE PROVIDE RECOMMENDATIONS WITH RESPECT TO:**

- (i) Policies and programs in general.
- (ii) Any models of policy and programs which are accessible/adequate/appropriate.
- (iii) Federal/Provincial programs, such as the Canada Assistance Plan, Canada Pension Plan.

APPENDIX C
KEY REFERENCES REVIEWED BY THE
TASK TEAM

KEY REFERENCES REVIEWED BY TASK TEAM

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APPENDIX D
LIST OF ORGANIZATIONS ENDORSING
DISCUSSION PAPER

LIST OF ORGANIZATIONS ENDORSING DISCUSSION PAPER

B.C. Association for Community Living
B.C. Coalition of People with Disabilities
B.C. Head Injury Association
B.C. Paraplegic Association
British Columbia Rehabilitation Society
Bulkley Valley Child Development Centre
Canadian Mental Health Association — Prince George Branch
Canadian Mental Health Association — Kelowna Branch
Canadian Pelvic Inflammatory Disease (PID) Society
Cerebral Palsy Association of B.C.
Community Support Team
Coquitlam Parks and Recreation
Disability Resource Centre
Family Support Institute
Greater Vancouver Mental Health Service Society
Greater Victoria Hospital Society
The Kinsmen Rehabilitation Foundation of B.C.
Kinsmen Rehabilitation Foundation — Kinsmen Mothers' March
Learning Disabilities Association of B.C.
Neil Squire Foundation
North Shore Community Services & Senior's Advisory Committee
North Shore Association for the Physically Handicapped
Post Polio Awareness and Support Society of B.C.
Registered Nurses Association of B.C.
S.P.A.R.C. of B.C.
Selkirk College
The British Columbia Society of Occupational Therapists
The Canadian Institute for the Blind
The Kinsmen Rehabilitation Foundation of B.C.
The Simon Fraser Society for Community Living
Victoria Vocational College

APPENDIX E

**MINISTRY OF HEALTH
PHILOSOPHY STATEMENT**

PHILOSOPHY STATEMENT

SERVICES TO THE HANDICAPPED

Ministry of Health service development to persons with a handicap and their families will be guided by the following philosophical principals:

- 1. Individuals with a handicap have the right to determine their own personal goals, the right to access to community services, the right to privacy, the right to appropriate health care, and all other rights enjoyed by other people.**
- 2. The Ministry of Health recognizes the importance of the family, natural or alternate, as the key resource and support for the development and care of persons with a handicap.**
- 3. Health services will be provided in the residential setting which is most appropriate to the medical, health and other human needs appropriate to the age and health status of the individual.**
- 4. The Ministry of Health, in consultation with individuals with handicaps, their parents, families and/or advocates, will provide the opportunity for optimal development of individuals' physical, intellectual and emotional potential with a view to both maximizing quality of life and providing as normal a lifestyle as is feasible.**
- 5. The Ministry of Health will attempt to provide services that respect the human dignity of individuals with handicaps and help prepare them for facing real, but prudent risks in the community.**
- 6. The Ministry of Health will facilitate the integration of individuals with a handicap into society.**
- 7. The Ministry of Health will plan and deliver services in a cost-effective manner.**

APPENDIX F
SUMMARIES OF RESEARCH PAPERS

I. SUMMARY OF "CATALOGUE OF SELECTED PROGRAMS AND SERVICES FOR PERSONS WITH DISABILITIES AND A DISCUSSION OF POSSIBLE PROGRAM AND SERVICE DEVELOPMENT PROJECTS"

(Marvin Shaffer & Associates Ltd., 1991)

The first section of this report provides information on selected government programs and services for persons with disabilities in British Columbia. A brief description of each program and service is presented under the following categories:

1. Income Support Programs
2. Housing and Residential Programs
3. Transportation Initiatives
4. Medical Service, Technical Aids, Equipment and Supplies
5. Home Support Services
6. Community Based Services
7. Employment, Training and Education Programs

The next section gives a synthesis of concerns raised in the public submissions to the Community Services Task Team.

Finally, the author discusses possibilities for the development of more comprehensive and responsive programs and services.

II. SUMMARY OF "A CRITICAL REVIEW OF THE GAIN PROGRAM"

(Marvin Shaffer & Associates, 1991)

This report reviews the income support system for persons with disabilities in British Columbia.

In British Columbia, a patchwork system of private and public insurance schemes results in varied treatment of persons with disabilities.

When a disability is a result of an activity where third party liability can be established, the person with a disability can seek compensation for the resulting loss in future income, the additional required financial resources to purchase disability-related goods and services, and, in some cases, compensation for non-financial losses. When liability cannot be established, general insurance coverage for interrupted earnings may provide financial resources to persons with disabilities. These insurance schemes are not universal and are generally limited to employed union and professional individuals.

Government managed and funded income "insurance" programs such as Unemployment Insurance, Workers' Compensation, and the Canada Pension Plan, may also provide income support to persons with disabilities.

For persons who fall through the "holes" in the insurance net, the government income support programs provide the backup income "safety net". The GAIN program provides the floor of income support for persons in British Columbia. The GAIN program guarantees a level of monetary resources based on a calculated level of "need" for the individual or family without a time limit.

This report reviews the GAIN program by examining the implications of the regulations and policies for persons with disabilities in need of income support and disability-related programs and services.

In the last section of the report, the author explores six policy options that begin to address the concerns identified in the review of the GAIN program.

III. SUMMARY OF "THE DISABILITY INCOME SYSTEM IN CANADA: A LITERATURE REVIEW AND POLICY ANALYSIS"

(Michael J. Prince, 1991)

This study reviews the literature on income security for persons with disabilities and provides an overview of reforms to the income security system in Canada, designed to improve the adequacy of income for persons with disabilities.

The report is organized in five main parts:

- Part I** Outlines the existing system of income support programs and related services, rights and duties in Canada.
- Part II** Identifies both the strengths and shortcomings of the overall system.
- Part III** Reports on international experience in fourteen western industrial countries with nationwide government plans providing benefits for long-term disability.
- Part IV** Summarizes the proposals for reforming disability income policy made by the works reviewed.
- Part V** Comments on the feasibility of the reform proposals in terms of administration, financing and political support.

The literature supports the view that Canada does not have a disability policy because there is no overriding strategy linking together the various programs available to persons with disabilities. Disability policy in Canada has generally been viewed as a sub-sector to social welfare and social security policy.

The literature advocates policy with the following values and objectives: income adequacy and security, individual rights and self-determination, equity or fairness in treatment, administrative efficiency, and policy comprehensiveness.

The preferred approaches to policy change are social insurance and income-testing. Moreover, employment initiatives and rehabilitation services are widely seen as integral parts of the disability income.

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